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ABSTRACT

This report contains highlights from a seminar on crack-using pregnant mothers and their babies. Comments by these panelists are summarized: Sonia Imaizumi, a pediatrician/neonatologist who has worked with inner city women who abuse drugs; Mary Jiordano, a social worker and family therapist, and director of Families First, a family preservation program in Detroit, Michigan; Linda Lewis, assistant deputy director for treatment and rehabilitation, Office of National Drug Control Policy, Executive Office of the President; and Doug Besharov, resident scholar at the American Enterprise Institute. These topics, discussed at the seminar, are summarized: (1) characteristics of women who abuse alcohol; (2) effects of cocaine use on the mother; (3) the continuum of crack use; (4) Florida's response to crack using mothers; (5) components of a comprehensive treatment program; (6) the emphasis on prevention; (7) child welfare; and (8) legislative proposals. A background briefing report is also included, which contains information about the scope of the problem, an overview of federal responses, new models of comprehensive prenatal and postpartum treatment programs, examples of four model demonstration programs, legal issues, state policy responses, and organizational resources. (37 references) (LLL)

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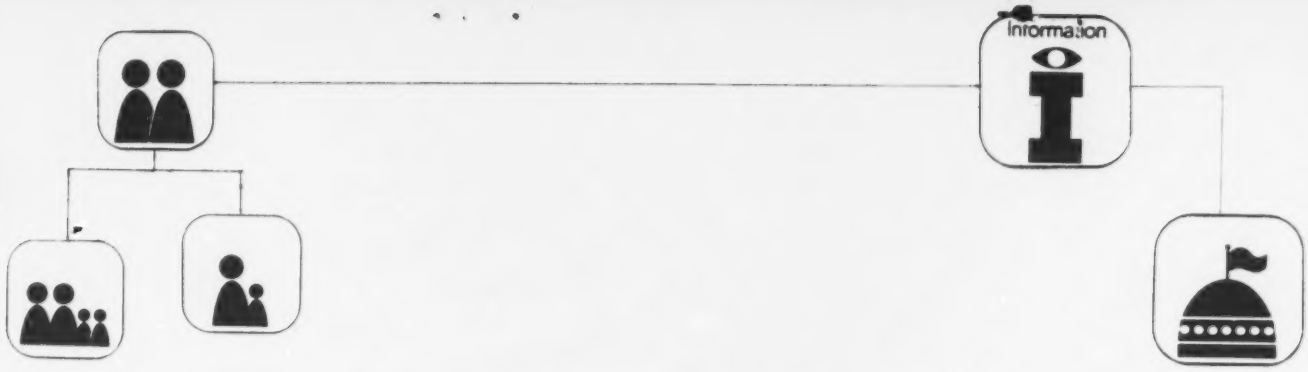

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DRUGS, MOTHERS, KIDS AND WAYS TO COPE

April 20, 1990 Mansfield Room (S.207), the U.S. Capitol

Panelist: **Sonia Imaizumi, M.D.,** pediatrician and neonatologist at the Medical College of Pennsylvania
Mary Jiordano, M.S.W., program director of Families First, Detroit, Michigan
Linda Lewis, M.S.W., assistant deputy director for treatment and rehabilitation, Office for National Drug Control Policy
Doug Besharov, J.D., resident scholar at the American Enterprise Institute

Moderator: **Theodora Ooms,** director, Family Impact Seminar

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BACKGROUND BRIEFING REPORT.....pages 1 to 31

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Drugs, Mothers, Kids and Ways to Cope

Background Briefing Report
and
Meeting Highlights

Theodora Ooms and Lisa Herendeen

This policy seminar is one in a series of monthly seminars for policy staff titled, *Family Centered Social Policy: The Emerging Agenda*, conducted by the **Family Impact Seminar**, American Association for Marriage and Family Therapy, Research and Education Foundation, 1100 Seventeenth Street, N.W., The Tenth Floor, Washington, D.C. 20036, 202/467-5114.

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Drugs, Mothers, Kids and Ways to Cope

Highlights of the seminar meeting held on April 20, 1990, Mansfield Room (S.207), the U.S. Capitol. (A supplement to the Background Briefing Report.)

In response to the many inquiries they received for information from congressional staff and executive agencies about crack-using pregnant mothers and their babies, the Office for Substance Abuse Prevention and the Bureau of Maternal and Child Health encouraged FIS to hold this seminar. The seminar attempts to moved beyond the well-known horror stories about maternal crack use and examine the research and trends that affect this problem, explained director, **Theodora Ooms** in her opening remarks. The seminar and report also look at "ways to cope" by presenting and writing about programs that are successfully treating these women and their families.

Sonia Imaizumi M.D., is a pediatrician/ neonatalogist who has worked extensively with pregnant women and mothers from the inner cities who abuse drugs---specifically methadone, in New York, and, more recently, "crack" in Philadelphia. She began with the general comment that though there has been a staggering increase in the use of cocaine by pregnant women, the long term effects of their drug use on their babies are still unknown.

Characteristics of women who abuse alcohol. Since there is very little national information available about the characteristics of crack using mothers, Dr. Imaizumi began with a review of selected facts about women's alcohol abuse-- which are much better known--since in her clinical practice she sees many of the same characteristics in mothers who use crack. Compared to male alcoholics, women alcoholics are more likely to experience severe financial problems, depression and other affective disorders, lower self-esteem, poly-drug abuse, and physical abuse. More than half report experiencing some type of child or adult sexual abuse. Women alcoholics are stigmatized and more likely to be referred for psychiatric treatment than men. In one study, 86% of a group of alcoholic women failed to mention their alcohol problem to their physicians.

Philadelphia study of perinatal cocaine use. Again in the absence of national data, Imaizumi reported on findings of a study to determine the incidence of cocaine use among 1000 mothers who gave birth in an eight week period in eight city hospitals in Philadelphia in 1989. Cocaine use was detected in an average of 16.3% of the mothers. (The frequency of use among the hospitals varied from 6.4%-24.3%.) Compared with non-users the cocaine users were more likely to be black, on medical assistance, and have a higher incidence of other substance use. An alarming finding was that 71% of cocaine using mothers have had no, or poor prenatal care compared with 15% of the non -user population. In the study the infants of users were smaller, born earlier and more likely to be in intensive care. Nearly 10% (compared to 2.5%) were discharged to a place other than home.

Effects of cocaine use on the mother. There are important differences between cocaine and its derivative "crack", Dr Imaizumi said. The effects of cocaine powder, which is usually snorted, have an onset within 5-10 minutes, peak in 15-30 minutes and last for 1 to 1 1/2 hours. The effects of the derivative "crack" crystals, which are smoked, have an onset within 5-10 seconds, peak within 15-20 seconds and last about 20 minutes. Crack is a very powerful central nervous system stimulant. Once the initial effects of extreme euphoria and alertness wear off, depression

and agitation sets in. Crack has very strong constricting effects on the arteries, and increases the heart rate and blood pressure. (Young healthy males who use crack have died of cerebral vascular accidents and myocardial infarctions.) Women who smoke crack regularly have a very high incidence of psychiatric disorders, however it is difficult to know whether they are taking crack to medicate a psychiatric disorder like depression or whether crack is causing their emotional problems.

Effects on the infant. What happens to the fetus during pregnancy? Imaizumi explained that since the molecule of cocaine is very small and lipid soluble it crosses the placenta fast and constricts the blood supply to the fetus and this lack of oxygen results in higher rates of complications in labor and delivery. A few animal experiments have tried to determine the teratogenic effects (i.e. fetal damage) of crack use but the results vary. While "crack" is clearly associated with low birthweight, prematurity, birth complications, and small head circumference there is no recognizable set of physical characteristics that mark a "crack" baby in the way that the baby with fetal alcohol syndrome is easily recognizable, or thalidomide babies. Also we do not know whether the effects are related to long term use or acute use right before delivery. Although Dr. Ira Chasnoff reports some complications with pregnancy even when mothers stopped using crack after the first trimester.

Imaizumi concluded by saying that the babies exposed to crack do react abnormally to their environment immediately after birth, but the long term effects are not known. Teachers are beginning to report that the children born in the first wave of the crack epidemic and are now entering kindergarten are very disruptive and have many learning problems. However, how much of this behavior to attribute directly to the drug itself or to the nature of the caregiving environment they grow up in remains an open question.

Ooms said that the next three speakers would focus on what kinds of efforts are being made to meet the serious, multiple needs of these women and their infants which Dr. Imaizumi had just outlined. Programs to treat these women and protect their children are being established in a variety of settings. The next speaker will describe an approach based in a child welfare setting.

Mary Jiordano, is a social worker and family therapist and director of Families First, a family preservation program in Detroit, Michigan. Families First, is a two year old program established in many sites throughout Michigan. It is an intensive 4 to 6 week intervention program that works with families when children are at imminent risk of removal. Caseworkers work with only two families at a time and provide them with whatever services they need, working in the families own homes. They may spend up to 20-30 hours with the family a week. The program philosophy is that children have a right to receive the care and treatment they need within their own homes if at all possible. The focus is on identifying families strengths, not their problems. The workers are trained to be culturally sensitive. In the Detroit program over 99% are Afro-American, a culture that has a long tradition of extended family assistance and support. The workers build on this tradition (see page 14 for more detail).

In the last eighteen months over half of the families referred to the Detroit program have been involved in substance abuse, mostly crack use. Jiordano pointed out that while the crack epidemic is devastating for families, these families are not as hopeless as media reports lead us to believe. She said that crack use has proven to be treatable for many families when an ecological approach to help families cope with the stresses in their lives is used. Crack is only one of a number of problems the families have so the services must be flexible to meet multiple needs.

Continuum of crack use. Crack use varies between individual users. It is important to assess the level of use for each client in order to plan appropriate treatment for the family. To illustrate this point, Jiordano broke down crack use into five types of users:
--occasional (one time every other month),

--recreational (approximately one time per month),
--weekly (approximately one to two times per week),
--continuous (3-4 times a week),
--and daily (one or more times per day.)

She noted that most mothers seen by Families First fall in the "occasional" category and those that fall in the "daily" category are rarely referred. She also pointed out that because crack is very addictive, a mother's frequency of use will increase unless it is stopped through intervention. Jiordano then outlined the approach that Families First has developed for dealing with these five different types of users, keeping in mind that safety and care of the children is always first.

Occasional/Recreational. For the occasional users, social workers will teach the mother a variety of coping skills. She is taught to keep a journal to identify events that trigger her use of crack, to plot times of the day or week when crack use occurs, and to record feelings, i.e. depression, anger, frustration, and overwhelmedness. Social workers teach her how to argue with her partner because she is often being taken advantage of in her own home. She learns how to set limits. She is encouraged to take time out for herself.

The mother often feels isolated thus, to help her overcome these feelings, she is assigned a variety of tasks such as becoming involved in school activities. She is also encouraged to establish support systems with reliable neighbors and relatives. She must list who she can leave the children with if, and when, she needs child care. Even if she is only an occasional user the mother is given information about treatment because her use will increase if she does not get help. The social worker will help her to overcome barriers to treatment such as transportation, child care, proximity to home and fears she has about attending treatment and may attend the first meetings with her.

Weekly/continuous use. For women who are weekly or continuous users, Jiordano explained that the focus of intervention changes. Safety and care of the children is the first priority and is discussed with the parent immediately. The social worker will work with the mother to establish a list of places the children can stay when the parent uses. The social worker asks the parent to instruct children (if older) what to do if she becomes impaired, i.e. who to call, where to go etc. The social worker encourages the mother to coordinate and enlist the assistance needed, so that she still feels in control.

Since most women deny the pain that their drug abuse is causing them and their families, the social worker will go over with the mother her daily routine and emphasize how her behavior is affecting the family. For example, help her see how the money that she spends on crack is taken away from buying food for her children. Examining her behaviors is the best way to get a women to realize the trouble she is in.

Similarly the social workers inform the mother about what the drug use is doing to her health. Next, and most important, the social worker explores with the mother the various substance abuse treatment options and they jcintly decide upon a plan. Many treatment programs are not well-suited for these women, Jiordano pointed out, as many programs were designed for white males and not this population. Finding a program that meets the needs of this population is difficult. However excellent treatment programs for women are now beginning to be developed.

Next, a safety net for the care of children is planned in conjunction with the mother in preparation for the mothers' drug use increasing. (Social workers are honest about telling the mother that she will probably get worse before she gets better.) Relatives willing and able to care for children during her treatment are identified.

Daily Use/"Bottoming Out" Point. When a mother is abusing drugs one or more times a day, the children's safety is the primary concern. A parent's daily use or "bottoming out" is

characterized by goods, food, and furniture being sold for crack. The parent is unable to address or plan for possible treatment, she is unable to follow through on treatment, and not ready to change. Sometimes this type of family is not referred to Families First for intervention, the children are immediately removed and placed in foster care. But when they are referred to the program, a social worker will talk with the mother about who she wants to have take care of her children. Her social network of reliable family members and friends is explored to see if they can provide care for the children. She may be asked to appoint one of these as a temporary guardian. The social worker may facilitate a family meeting with extended family and the children present where the mother's illness is explained and her inability at present to care for the children. Once the children are resettled, the social worker can work with the mother to determine the frequency of her use and then discuss with her what she would like to do about it.

Jiordano concluded by telling the audience that by doing all these things, Families First has cut significantly the need to move to foster care as a first resort when children are in crack- using homes. Over the past eighteen months, in 75% of all crack cases referred to them, the children have been able to remain with their mothers, in 15% they were placed with extended family, in less than 5% were they placed in foster care.

Linda Lewis, now assistant deputy director for treatment and rehabilitation, Office of National Drug Control Policy, Executive Office of the President formerly administered all drug and alcohol abuse treatment programs in Florida. Lewis spoke about Florida's drug problem, their expanding treatment programs and how Florida's experience can help other states.

To put Florida's experience in perspective she first gave a few statistics: 60% to 70% of the nation's illegal drugs come through Florida; 900 new residents enter the state each day; and the largest public health service they needed is alcohol and drug treatment which translates into about 28,000 new people needing that service per year. Florida also ranks 3rd in the nation for cumulative AIDS cases, and first in the nation for babies with pediatric AIDS. Based on an early hospitals survey, administrators projected that some 5,000 infants might have been exposed to drugs in the state which prompted the state to begin to take action.

Florida's response to "crack" using mothers. The situation in Florida has heightened so much since 1986 (when crack first hit the market) that 60-70% of all admissions to drug and alcohol treatment programs are now either crack or cocaine addicted. In response to the epidemic which has hit women particularly hard, Florida has amended its basic child abuse and neglect legislation to view drug dependence in a newborn as evidence of maternal child abuse. The Department of Health and Rehabilitation Services responded with a regulation mandating public health nurses, child welfare workers, and those in the health care system to report any suspicion of pregnant women's drug use. Along with these actions, the state developed new publicly funded treatment programs for these women in every area of the state (see page 17-18). Until this time, most drug and alcohol treatment had been based on male-oriented treatment models.

Components of a comprehensive treatment program. Lewis explained in developing their new program plans, Florida decided to look at what works for drug using pregnant women. Operation PAR, (Parental Awareness and Responsibility) began adapting its program for women about two years ago and is now an excellent example of a treatment model oriented to pregnant and post partum women (see page 14). The state has found that women in programs like PAR's, need educational and vocational skills training and most importantly, child care. Florida now funds child care as part of a comprehensive package of services. This package includes: outreach intervention specialists, residential and day treatment options, and educational and vocational services in every phase of treatment.

A state-funded treatment center can contract out or provide child care on-site in treatment programs as Operation PAR does. Besides making involvement in treatment easier for the mothers, quality

child care can improve the childrens' development which is often delayed due to their mothers' drug use. Parenting skills and prenatal care are also important components for treatment programs as well as partner counseling and family therapy which helps families to come together to support one another.

PAR has created PAR Village, an unique idea that other states may want to try. The program has relocated county-owned houses on a small tract of land to make a village for program participants and their children to live in while they are involved in the recovery program.

Evaluation. Florida has established a comprehensive data tracking program to follow the patients progress in treatment, which is being adapted for the new emphasis on these young mothers. Florida's assumption is that getting women into treatment early, during pregnancy, will produce positive results. In order to test this assumption, Florida will contract with Dr. Ira Chasnof to conduct a study to compare the birth outcomes of infants whose mothers have been in treatment versus the birth outcomes of infants whose mother have not been.

Funding. Within Florida, a combination of OSAP demonstration and NIDA research grants as well as ADAMHA block grants funds (using the special set-aside for pregnant drug-users) has been used to develop services for this population. A network of neonatologists working on this topic has also been set up within the state to share research, work on group projects, and collaborate on basic treatment programs ideas.

One good outcome of the public spotlight on this issue, said Lewis, is if a program is going to market itself as serving pregnant women, in order to get public funds then it must have all the right components. More and more states, like Florida, are developing substance abuse treatment programs specially tailored for pregnant women and their children.

This is a highly emotional issue. State and national legislation will focus on "the crack babies " said Lewis, but prevention services must be targeted on the women. Aggressive outreach to identify drug using pregnant women in health and social service programs like welfare services, food stamps and Medicaid funded programs is a good place to start. She predicted that this problem will soon push mainstream health care into the area of substance abuse treatment.

Doug Besharov, a resident scholar at the American Enterprise Institute, spoke about prevention, treatment , and child welfare issues, and directions for Federal policy. He began his discussion by agreeing with Jiordano that it is important to keep in mind that there is a wide range of levels of addiction. There are some crack users that have their crack use more or less under control, he said, but they pose a very different type of problem from the serious compulsive user. Many of the recent disagreements and debates---for example about whether children should be taken away from their crack-using mothers---have arisen because people are talking past each other, focusing on different parts of the spectrum of abuse. Policies need to be developed to address *all* levels of addiction, he stressed. However, he stated, most of his comments focus on the heavy, compulsive users.

More emphasis on prevention. Little is being done to prevent women from using these drugs, in the first place, said Besharov. One area where he sees hope is in the recent expansion of Medicaid eligibility to all pregnant women and mothers with children under one year of age at 135% of the poverty line. He urged policy makers to watch how this expansion should be implemented, how prenatal programs are established, and what is being done about outreach to address the problem of substance abuse in this population. Some innovative approaches are being tried---prenatal mobile vans for example. But even when prenatal care is available, he said, many of these women don't realize they are pregnant or are so absorbed in the pursuit of crack that they

don't care about getting prenatal care. We should also realize that there is a limit to the tolerance that voters have for this kind of extra (expensive) outreach, he added.

Improve birth control options. Since many of these addicted mothers are having second and third children, more aggressive family planning would help, he said, but effective birth control methods are difficult to deliver to this population. Besharov believes that Norplant---a type of birth control that is implanted in a woman's arm and prevents pregnancy for five years---which is currently being tested by the FDA, has the potential to help this problem tremendously. It would give young mothers some real options and, through their avoiding having more children, provide them with another chance to get off drugs and get their lives together, he said.

Treatment approaches. The compulsive users are very hard to reach, said Besharov. Cocaine is proving to be much harder to deal with than heroin because methadone was developed to help stop the compulsion for heroin. For crack there is no such blocker yet and crack is more addictive than heroin. Besharov urged policymakers to be careful that the increased dollars for treatment---including the 10% set aside in the block grant---be targeted on the full range of the spectrum of users, and that programs be carefully evaluated. He also advocated that a much more formalized public drug treatment system be established that include intake, treatment monitoring and follow-up services because relapse is so common.

Child Welfare. Crack-cocaine is the biggest problem facing the child welfare system today. Child welfare cases are a pyramid, said Besherov. At the top of the triangle are the most severe cases: homicides and sexual abuse cases. At the bottom, making up a million or so cases a year, are what case workers call "general neglect", which are essentially poverty-related neglect. These are often unmarried teen mothers who don't work and have trouble caring for themselves and their children. But since they didn't kill their children, and usually got their children to school, caseworkers could neglect, neglect. But now, crack-cocaine has hit that part of the child welfare caseload.

Nationally there is a 30% increase in the number of children placed in foster care in the last two and a half years. The rise, said Besharov, is directly attributable to crack/cocaine. In terms of the overall caseload in those communities, it hasn't grown that much. What we have is the same caseload being hit with another social problem, said Besharov. It is not that we have another group of more neglectful or abusing parents.

Contrary to the popular view, the best estimates are that only 20-30% of crack addicts' children are removed. Some think that number is too high and others think it is not high enough. But, he pointed out, opinions about whether that number is too high or too low are a function of the quality of treatment services and the alternatives.

Proposals for the Child Welfare System. There are a number of ways the child welfare system could be shored up to help deal with this new problem, Besharov said. Some believe a major increase in child abuse investigators is needed, but in his view the bigger problem comes with the very high caseloads of workers who take over after the initial investigation is complete. Also clearly we need an increase in the number and quality of foster care providers. But this is difficult to achieve since foster care agencies are competing for women with the labor market now.

What concerns Besharov is that we are not even talking about the 10% or less of those children of the hard core abusing mothers whom we do not know how to treat, and probably will not for another 5-8 years or so. We should be planning permanently for their needs, he said. But the issue of terminating parental rights in these situations is hard to face as we don't want to call any parent hopeless. Thus we are caught up in a symbolic crusade over what this debate is all about: whether it is about children's rights or women's rights.

Legislative Proposals. The current options facing the congress and the administration are quite limited, said Besharov. There have been proposals to increase Title IVB foster care service funds by $50-100 million or more. But one problem with this proposal, he pointed out, is that states already spend a lot of state money for IVB eligible services, so if Congress put another half a million Federal money into IVB, most states could claim it without expanding their current services. (In other words federal money would simply substitute for state monies.) Of course, he pointed out, some would use this new money to expand services, but this process would be uneven and unpredictable.

Another option is to increase funding under IVE of the Social Security Act, which is the basic funding stream for foster care maintenance for AFDC eligible children. But this would exacerbate the two-tier system that already exists---since many non-AFDC children receiving child welfare services would not benefit from such an expansion---and again, states could claim this increase in funds without expanding services to the population.

Both of these options are not very appealing to politicians who would prefer to be the author of a bold new program, rather than the author of a program expansion.

The Ways and Means Committee is considering a new proposal which has promising potential, Besharov believes, for responding to this crisis. The Committee is considering a demonstration program which will allow five to ten states---through the waiver mechanism---to reorganize and unify their child welfare services, maternal and child health services, tap into the education system, welfare reform funds, child care funds etc. to help this low income population (at risk of substance abuse, neglect etc.) Because we don't know how to reach this population successfully, said Besharov, we should let 5-10 states experiment for 5 years and evaluate the results.

He said he believed this proposal, which is still in the preliminary stages, signifies the beginning of a radical reorganization of services necessary to meet the changing needs of many low income families.

Points Made During Discussion

- Many substance abusing mothers are already involved with the criminal justice system---in probation, on parole or in jail, said a participant. Criminal justice sanctions have been found to keep women in treatment. Judges and probation or parole officers should be linked with treatment programs and monitor their attendance and progress. If we are talking about a wholistic approach then the criminal justice system needs to work closely with the drug treatment system.

  This comment started a long back and forth discussion about the complex issues involved in mandatory testing, reporting and criminal or treatment sanctions for substance abuse in pregnancy and drug-exposed infants. Theodora Ooms pointed out that a new publication by the ABA is a very useful resource in helping to understand the legal and ethical issues and distinctions (see Larsen, 1990). Among the points made in this part of the discussion were:

  --Health care professionals, said Imaizumi and others, are very worried about the barrier effect of equating prenatal substance abuse with child abuse. They believe that if the word gets out on the streets that doctors will report a positive urine test, pregnant crack users will simply not come for prenatal care or will refuse to have their urine tested.

  --An administration official pointed out that a similar worry 20 years ago was expressed at the idea of mandatory reporting of child abuse, but proved unfounded. Reporting prenatal

substance abuse is not the same as criminalization. A report of abuse should lead to the offer of treatment services. In response, several participants pointed out there was a considerable difference in the two situations--abuse that occurs prior to birth and abuse that occurs after birth.

--The numbers are so tremendous, a question was asked, if you start reporting prenatal substance abuse, what would you do with all the children? Take all the children away from mothers like you do with proven child abuse and neglect? Reporting does not automatically lead to placement was the reply, it triggers treatment services.

--The issue of routine testing of all pregnant women or all newborn infants was clearly highly controversial. However Besharov said that there should be no question of reporting when a hospital has already determined that the baby is drug exposed and will be returned home to an environment with significant drug abuse. "We are not talking about criminalization here but simply initiating a child protective investigation and getting the mother and child into treatment, which we have a moral responsibility to do," said Besharov.

--There is a definite professional bias toward testing and reporting low income black women and excluding white middle class women.

- We do not have nationally representative data on the incidence and prevalence of drug exposed infants. The research, as reported in the lay press is misleading, said an epidemiologist from NIDA. The most commonly used statistic that says that 375,000 babies are being born exposed to drugs each year is based on a small pilot study, not a national study. The term drug-exposed is an ambiguous term since it could mean merely that a mother used a drug once during her pregnancy or that she used drugs continuously. Also from the studies to date he said, we don't know how many drugs the mothers are using, what kind of drugs or how often. NIDA is funding several new studies which should help answer some of these questions including a national study of 8000 women whose results should be available in late 1992 (see page 3).

- A participant mentioned that in the alcohol treatment programs that she knew in Denver almost 100% of the women in treatment were in abusive relationships and that they were involved with alcohol as a form of self-medication. She wondered whether or not the women in these programs described by Jiordano and Lewis are in abusive relationships? Jiordano responded that while they do not formally screen for abuse they do have guidelines to assess whether there is any kind of violence in the families and deal with it when it comes up and it is quite common.

  Lewis responded that in Florida and in many states there is a comprehensive assessment done on anyone who seeks treatment which includes any experience of child or spouse abuse. Dealing with violence becomes part of the treatment, she said. She wished that other service systems were, in comparable fashion, screening for alcohol and drug use the way we are assessing for violence.

- Lewis pointed out that much time in the discussion period had focused upon what do we do about the infants after they are born instead of talking about needed prevention measures such as outreach, screening, and education. She urged the audience to focus more on what we can do about prevention rather than endlessly debating the numbers or the issue of mandatory reporting.

- Do the treatment programs target adolescent parents and the older children of drug abusing women, asked a participant? Jiordano replied that because Families First is an intensive, short

term program that works with the whole family, not just the mother, they try hard to identify other needs in the family and link that person with needed services. Thus when they identify a teenager who is taking on a parental role in the family they encourage her to be involved in outside activities and to perhaps attend Alateen and Alanon.

Lewis added that when you look at who is at risk (of becoming a crack using mother) you are looking at very young girls. Hence in Florida they do special outreach to high schools that have pregnant teenagers in them. It's a population that states must make sure to not leave out.

Imaizumi noted that in her program, the mothers' mean age was 25 years and they were nearly all ex-teenage moms that at 25 find themselves with two or three children and then get desperate enough to turn to crack.

- Has Families First followed up the families later to see if the women they helped are doing better? Jiordano replied that they indeed follow up with the families, 3, 6, and 9 months down the line. She said it is heartening to see a year later a baby developing normally, which many of them are. But she has also seen the baby at home connected to a heart monitor where he or she will probably die at home. But in any case when we see that the family is still together that is a measure of success for us, said Jiordano.

- Ooms concluded by saying that a lot is being learned about this population and how to help them but much more needs to be learned. We only heard about a handful of the exciting new program approaches today. She pointed out that the Coalition on Alcohol and Drug Dependent Women and Their Children has a committee on treatment that is conducting an extensive telephone survey of the 25 newly funded OSAP programs. This committee will soon have a report out with program profiles which should be very interesting (for more information see p. 20).

* Additional Reference: Since this seminar was held a new congressional report has been published on the topic:

Committee on Ways and Means, Subcommittee on Human Resources, U.S. House of Representatives. **The Enemy Within: Crack-Cocaine and America's Families.** Report prepared by the committee staff. Washington D.C.: U.S. Government Printing Office, June 12, 1990.

** Additional Organizational Resource:

Jacobs Institute of Women's Health.

This new institute is an independent, nonprofit organization founded by the American College of Obstetricians and Gynecologists (ACOG) in January 1990. It is planning to sponsor a conference on the role of primary care physicians in the treatment of substance abusing women of childbearing age. A number of organizations are involved in planning this conference including the American Academy of Family Physicians, the American Academy of Pediatrics, ACOG, the American Medical Association and the March of Dimes. A goal of this conference will be to develop a set of recommendations for these participating organizations.

The Jacobs Institute publishes a quarterly journal, *Women's Health Issues* and is conducting a project to increase the rates of mammography screening in women over age 40. Contact:

Martha Romans, Director, Jacobs Institute of Women's Health, 409 12th Street S.W., Washington D.C. 20024 202/863-4990.

**Additional Reference:

Youth Law News, Vol. XI, No. 1, 1990, special issue on maternal substance abuse. Available from: the National Center for Youth Law, 114 Sansome Street, Suite 900, San Francisco, Calif. 94104, (415) 543-3307.

DRUGS, MOTHERS, KIDS AND WAYS TO COPE

Background Briefing Report

INTRODUCTION

The subject of drug abuse, pregnancy and motherhood arouses strong emotions. Among the most common reactions are anger towards pregnant women and mothers who abuse drugs combined with a strong desire to protect their children. Yet many also feel compassion for these women who are seen to be victims of their environment and of societal indifference to their needs. The urge to find solutions to this problem is fueled by media reports which, unfortunately, tend to propagate myths and stereotypes and suggest we know more than we do.

There is widespread agreement that the problem of drug abuse---especially of "crack" cocaine---by pregnant women and mothers of infants and young children is very serious and clearly getting worse. The costs in terms of human suffering and wasted potential, professional burnout and public service expenditures are staggering. Yet we have very little information about the extent and nature of the problem or its long run consequences. Nor is anything known about the relative costs and effectiveness of various prevention or remediation strategies.

The nationwide alarm is leading to intensive efforts to do more and learn more. The problem has so many aspects and ramifications---medical, legal, ethical, social---and is so intertwined with other issues such as AIDS, that it is easy for policymakers to become overwhelmed and confused about what directions to take and which issues have priority.

Policymakers and program administrators are confronting many extremely difficult questions. Is their primary obligation to safeguard the health and protect the well-being of the fetus/ child or is it to provide medical and drug treatment to the substance abusing expectant mothers? Are these two approaches mutually exclusive or can they be combined? How many of the drug abusing mothers, if any, can be helped to become "good enough" parents? Are mandatory testing and reporting and other punitive sanctions needed to get these mothers into treatment programs or do they have the opposite effect and drive the mothers away? Should the termination of parental rights be made easier in certain situations of parental drug use? Do we know what these are?

A family issue

Too often this debate at the national level deteriorates into a simplistic contest between those who primarily advocate for the protection of the fetus/child and those who advocate for the health care needs of the mother. The reality is more complex: the problem affects not just individuals but the functioning of *families*. In fact the day to day, painful decisions that have to be made by health care and social service personnel and the courts, require a sensitive and informed balancing of the needs and rights of mother and child together with a concern for the integrity of the family as a socially functioning unit.

Clearer policy directions emerge if the problem is viewed primarily as a family issue rather than a medical or child protective issue. If the problem is viewed solely as a child protective issue it is argued that when an infant's urine tests positive for drugs the presumption should be that he/she will be removed from the parents. This presumption could then only be overridden by strong evidence that the parents were serious about enrolling in a drug treatment program, regularly visited the infant and were otherwise fit to be parents.

In contrast, if it is viewed as a family issue, the first presumption is to strive to keep the family together through providing preventive and treatment strategies which assure the child is protected and safe while the mother works on improving her capacity to be a parent and enrolls in drug treatment etc. Only if these efforts are tried and fail should child placement be considered. (Such an underlying principle is consistent with the goals and assumptions of the present public child welfare system.)

Even if protracted periods of foster care were not considered harmful to children---which most believe is in fact the case---realistically there will never be enough foster, adoptive homes for all the children of mothers who abuse drugs. Nor is the punitive, "pregnant mothers must be taken into custody" approach likely to be constructive: it may drive her underground at the very time she needs treatment, and it will not prevent her, after her release, becoming pregnant again.

A realistic family-focused approach acknowledges that there are some family situations when the child must be found another home on either a temporary or permanent basis. But even in this situation a family-centered strategy suggests that resources must be put into finding and supporting substitute foster or adoptive families and providing them with the training and resources they need to be good enough parents.

This background briefing report first reviews what is known about the nature and extent of perinatal substance abuse and the effects on mother and child. Then we review the current federal policy framework, service delivery and legal issues and the key features of promising treatment programs and state initiatives. Finally we briefly describe two current legislative proposals for expanding and improving the nation's response to this problem. The key questions are: Do we know what kinds of preventive and treatment approaches and policies are needed to implement this family focused strategy? And what is the role, if any of mandatory testing, reporting and treatment in supporting these goals?

SCOPE OF THE PROBLEM

(Sources: Chasnoff, 1989; Chasnoff, ed. 1988 and 1986; Daghestani, 1988; Edgar *et.al.*, 1989; Eliason and Williams, 1990; Howard *et al.* 1989; Jones and Lopez, 1988; Kennard, 1990; Khalsa, 1989; Kusserow, 1990; Littlejohn & Thomas, 1989; Petrakis, 1987; Select Committee, 1989; Sullivan,1990; Weston, *et. al.* 1989)

Quality and availability of data.

While there is a great deal of information on the extent and effects of perinatal alcohol abuse, there is a dearth of information about the problem of perinatal illegal drug abuse and its effects on children. There are no national studies of the prevalence of substance abuse in pregnancy or the postpartum period or of the characteristics of women who abuse drugs during pregnancy. And there are very few longitudinal studies of the effects of maternal cocaine use on children.

Studies that do exist are generally small scale and based on unrepresentative samples. Incidence data reported are usually very global and not very reliable. For example, the data presented are often unable to make important needed distinctions about the frequency and degree of substance use/abuse or between different types of substances both legal and illegal.

Information about rates of perinatal substance use/abuse is usually obtained from pregnant women directly in self-report surveys or in clinical interviews. It is believed that these methods lead to considerable underreporting of the extent of substance use/abuse especially with respect to illicit drug use. These data are sometimes supplemented by test results from maternal or fetal urine samples but again these are only a crude indicator since they can result in false positives, they only

indicate drug use within the last couple of days, and seldom distinguish between the type of drug used etc. Moreover all of these incidence studies only provide a measure of fetal drug *exposure*, they do not inform us about the type or severity of problems these babies may have as a result of their exposure to drugs.

Moreover testing mothers or their infants for drugs is not required by law in most states nor is it a routine clinical procedure in most hospitals but is normally requested by physicians only when there are other reasons to suspect drug abuse. Routine testing sometimes occurs in clinics or hospitals with high proportions of low income, minority populations and other risk factors. Hence we do not have good information about the extent of the problem in suburban, rural or middle income communities.

The only information about the characteristics of the drug abusing mothers comes from small clinical samples. And even in these there is virtually no mention of the babies' fathers. We do not have any generalizable data on the mothers' age, marital status and family characteristics, employment or welfare status. We do not know about their husbands or living together partner's patterns of substance abuse, employment status, or whether their children's fathers have established paternity or are paying any kinds of child support. All of this information would be very useful in designing any significant new policy strategy to combat the problems of perinatal substance abuse.

Within five years a great deal more will be known about the problem. The Division of Epidemiology and Prevention Research, National Institute for Drug Abuse (NIDA) is funding several major new studies including the In Utero Drug Exposure Survey, a study of 8,000 randomly selected pregnant women and several 3 - 5 year studies of the longitudinal effects of perinatal cocaine use including one in Washington state on white, middle income cocaine users. The Center for Disease Control, Atlanta is conducting a major study of Maternal Cocaine Use, Birth Defects and Low Birthweight. In addition, questions related to prenatal drug use have been added to the Department of Labor's National Longitudinal Survey and to the National Survey of Family Growth.

Population "at risk": substance abuse in women of childbearing ages.
(Sources: Besharov, 1989; Dhagestani, 1988; Edgar et al. 1989; Eliason & Williams, 1990)

The dangers of smoking, drinking and heroin use during pregnancy have been known to health care professionals for several years, yet public attention has only recently focused on the problems of perinatal drug use/ abuse, perhaps because the problem has only recently become more visible. In recent years there has been a steep increase in the rates of women of childbearing age who are using illicit drugs, especially "crack" cocaine.

Whereas cocaine was primarily used by the middle class in the 60s and 70s, in its derivative form known as "crack" it has spread widely among the lowest economic groups in the mid- 80s. "Crack" is much cheaper than cocaine, and easier to use, and is more highly addictive providing an instant "high". Instead of being ingested through the nose through snorting or sniffing as cocaine powder is, the "crack" crystals are usually smoked in a pipe ("crack" can be injected). For reasons that are not entirely clear, women have been using "crack" in increasing numbers, so that in some communities they are abusing "crack" at the same rates as men.

In the National Household Survey on Drug Abuse conducted by NIDA in 1985, 14% of women ages 15 - 44 had tried cocaine at least once compared with 23.2% of men the same ages. 3.5% of young women were current users of cocaine, defined as those who had used in the past month, and 5.3% of 15-21 year old women were current users. Overall the survey estimates that 6 million women in this age group had used one or more illicit drugs in the past month, and of these an

alarming number, about 1 million, appear to be current users of cocaine. While white women are more likely to have ever used cocaine, black women are more likely to be current users. (Note: research to date does not distinguish between use of cocaine or its derivative "crack" cocaine.)

Many women who abuse drugs will become pregnant and continue to use cocaine without realizing that they are pregnant. Many never receive prenatal care or receive it only in the last trimester, a disturbing fact since it is in the first trimester that the damaging effects of drugs on the fetus are most strong.

It is only in recent decades that researchers began to understand how many toxic substances pass through the placenta to directly affect the developing fetus. In Europe, the extensive birth defects caused by the prescription drug Thalidomide, a sleeping pill taken during pregnancy, brought to the public's attention the damage that drugs taken by the pregnant woman can cause to the fetus.

The association of maternal abuse of alcohol during pregnancy with birth defects became recognized as a problem in the early 70s when the earliest studies identified and described the Fetal Alcohol Syndrome (FAS) a recurrent set of physical anomalies and behavioral problems commonly occurring in the children of mothers who are alcoholic. FAS is one of the leading known causes of mental retardation. A common estimate of overall incidence in the U.S. of FAS is 1-3 per 1000 live births, i.e. 3,600-10,000 FAS births each year. In some population subgroups the rates are much higher, such as certain American Indian tribes which have closer to 1 FAS per 100 live births. There is as yet no general agreement about what levels of alcohol use are teratogenic.

Prevalence of prenatal and maternal substance abuse.
(Sources: Besharov, 1989; Chasnoff, 1989; Finnegan, 1988; Khalsa, 1990)

Contrary to the impression created by the media headlines, reliable national data on this issue is very scarce. The most often quoted study, conducted by Dr Ira Chasnoff in 1988 has some of the limitations cited above (for example, the sample was not nationally representative, the drugs tested for included marijuana and the study could only assess drug use at one point in time.) Nevertheless it is the best study available to date. Dr. Chasnoff surveyed 40 hospitals in different geographic areas serving patients from a range of income groups. Based on reports from 36 of the hospitals he found that the overall incidence of substance abuse in pregnancy based on discharge diagnosis to be 11% with a range of 0.4% to 27%. These rates have been extrapolated into an estimate of 375,000 drug exposed babies born each year in the U.S.

Studies of the incidence of newborns exposed to "crack" in cities which report a severe problem suggest that Chasnoff's national estimates are too high. For example, a study in N.Y. City estimated 5% of all live births were exposed to "crack" and a study in Washington D.C. estimated about 15%. Based on these figures Besharov estimates a national total of 1 - 2% of all live births or 30,000-50,000 babies exposed to "crack" each year. The President's National Drug Control Office estimates that 100,000 cocaine exposed babies are born each year. The HHS Inspector General's report, based on interviews in 12 metropolitan areas, confirmed this more conservative estimate of cocaine exposed babies.

Two interesting points emerged from Chasnoff's study. The reported incidence of substance abuse in pregnancy rose with the degree of thoroughness of the hospital's assessment. And the incidence of substance abuse was quite unrelated to the proportion of patients receiving public aid at a particular hospital. In other words, drug use during pregnancy is a problem across all income groups although public attention has only focused on the problem amongst the poorest groups.

Other area/ local studies have reported dramatic increases in the use of cocaine/crack use in pregnancy in certain cities. The House Select Committee on Children, Youth and Families,

conducted a survey in 1988 of 18 metropolitan hospitals. Fifteen of these hospitals reported 3 - 4 times as many drug-exposed babies since 1985. In a local study in Philadelphia, at one city hospital in 1984, 7% of pregnant women were diagnosed as "crack" users, but by 1987 this number rose dramatically to 58% (Select Committee, 1989).

Effects of "crack" cocaine use on the pregnant woman/ mother.
(Sources: Angelini & Gibes, 1990; Chasnoff, 1986; Sullivan,1990;)

Clinicians have been appalled at the rapidity with which women become addicted to crack, and at the intense compulsivity of their addiction so that their whole life becomes organized around finding the next dose of "crack". They emphasize that in many of these respects crack is totally different from other illegal drugs and infinitely harder to treat. These clinical reports of individual cases are undeniably alarming, but have led to a good deal of stereotyping and undocumented generalizations about all drug using mothers which can lead to somewhat simplistic and drastic solutions. As mentioned above there is no national profile available of the socioeconomic characteristics, family background and status of pregnant women and mothers of young children who abuse drugs. Nor is there any national data on their patterns of drug use.

"Crack" cocaine has serious negative effects on the pregnant woman's health and behavior and it is frequently accompanied by use of other drugs. In addition, in the clinical, urban, low income populations primarily served and studied, "crack" use is only one of a number of serious problems the woman is having to deal, with many of these are associated with poverty. Addicted mothers in inner cities live in very poor housing, in neighborhoods scarred by the drug trade, and are frequently isolated and without a social network of support.

To sustain their habit many women barter sex for drugs. Many have partners who are intravenous drug users. Thus many "crack" mothers are in double jeopardy of developing AIDS. "Crack" use is associated with loss of appetite and poor nutrition and repeated episodes of sexually transmitted diseases. The women are often clinically depressed, anxious and have poor self-esteem. They come from highly dysfunctional families, and have frequently been victims of child sexual and physical abuse. Clinicians report the mothers seem irritable, highly anxious and show erratic behavior. They frequently fail to keep appointments.

Occasionally women will develop serious organic reactions to "crack" cocaine use of psychiatric proportions including violent and aggressive behavior, paranoid delusions, and acute physical reactions such as seizures or cardiac arrhythmias which can result in death.

One of the major unfortunate results of their abuse is the negative reactions these mothers receive from the helping professionals. It is very difficult for professionals to sustain the empathy and non-judgmental attitudes needed to maintain a treatment relationship with these women. Feelings of anger and punitiveness directed towards the mothers, and fantasies of rescuing their children are very common.

Media headlines have often reported that "crack" 'kills the maternal instinct' and that "crack" babies 'have no parents' and suggest that efforts at treatment are fruitless. Yet reports from model programs specifically targeting these women suggest that when treatment programs are specifically designed to meet their needs, they can help many of these women. The impending birth of their child often provides the motivation and catalyst some women need to moderate or discontinue "crack" cocaine use during pregnancy, and after the baby is born. And such women do then make constructive use of a range of treatment and other services provided to help them function better as women and as mothers.

Effects on the infant/child.
(Chadwick; 1988; Howard *et.al.*, 1989; Kennard, 1990; Weston *et.al.* 1989)

There are several types of direct effects of drugs on the developing infant: some drugs are addictive for the infant (such as methadone), and after the baby is born it will go through a period of withdrawal and then will probably develop more or less normally. Others, are toxic and can cause direct, permanent injury to the infant and they, together with the addictive drugs may cause the newborn to be sick, small for gestational age, low birthweight and premature. Finally there are some drugs that are teratogenic, i.e. they cause malformations of specific organ systems or the extremities to occur in the developing fetus. Some of these defects may be evident at birth others may not emerge for months or years.

Clinical studies have found that babies exposed to cocaine during pregnancy are more likely to have their growth retarded, to have smaller head circumferences, to be born prematurely, have low birthweight, and exhibit several types of neuro-behavioral deficits in the newborn period. They are at greater risk of spontaneous abortion and abruptio placenta. A few have malformations of the uro-genital tract. They appear to be at somewhat higher risk of Sudden Infant Death Syndrome. The nature and extent of any brain damage that may occur is still unknown.

Babies exposed to cocaine in utero do not exhibit serious withdrawal symptoms and yet are often very difficult to care for which is a serious barrier to helping their mothers bond with them early on. They tend to exhibit irritability, are difficult to satisfy, comfort or quiet, and may have trouble communicating their state or needs. Such babies make their caregivers feel quite inadequate and incompetent. In a follow-up study of 263 drug-exposed babies at age two Dr Chasnoff found that the children scored in the normal range for overall intelligence, but seemed to run some risk of developing learning disabilities and delayed motor, speech and language development. (However it was difficult to know how much of these problems were a result of the environment in which they were growing up.)

Long term follow up studies have not yet been done to follow a group of drug exposed babies into school, but some clinician researchers believe it likely that cocaine causes long term brain damage which is likely to show up in learning and behavior problems at school age.

"Crack" using mothers often have IV drug users as sexual partners. Hence their children are at substantial risk of developing AIDS. Approximately 2,000 cases of full blown pediatric AIDS cases have been reported to the Center for Disease Control to date, and the majority of these by far are infants,who develop the disease through transmission in utero. (Older children develop AIDS through blood transfusions.) It is estimated that three to four times this number are HIV infected.

The numbers of infants with AIDS is clearly increasing. A recent Center for Disease Control report of a nationwide testing of 2 million newborns in 1989 revealed that 4,500- 6000 of HIV infected women gave birth resulting in between 1500-2000 infected babies (Washington Post, April 3, 1990).

Clinicians are also worried about the indirect effects of maternal cocaine use on children, through its negative effect on the mother's caretaking and parenting abilities. Many of these infants require more than ordinary parenting which this group of mothers in particular often has a very difficult time providing. When these drug-exposed babies are provided with a range of early intervention services, clinicians find that many of their difficulties can be alleviated. But these services are much more effective when reinforced by the parent who needs to be taught and shown how to stimulate her baby, learn how to soothe and quiet it and so forth.

Effects on the Medical and Child Welfare Service Systems.
(Sources: Besharov, 1989; Beyer, 1989; Feig, 1989; Howard, 1989; Kusserow, 1990; NBCDI, 1989)

Responding to the problems of drug-exposed babies and their mothers has placed a severe strain on the medical and child welfare systems in those states and communities which have high rates of "crack" cocaine use. The costs of medical care provided to the baby alone are extremely high since so many of them require extended stays in premature intensive care units where they receive highly expensive treatment which may average around $18,000 per child, but can, if there are complications, cost up to $135,000. Even those babies born at full term may require extended stays due to withdrawal symptoms or other medical complications. Added to these immediate costs are the costs of longer term "early intervention" services. Finally, there are the unnecessarily high costs of those babies who remain in hospital not for medical reasons but simply as "boarders."

Since the large majority of these babies receive public aid most of the costs of their medical care are paid for by Medicaid, but many hospitals report shortfalls in reimbursement and that they have to absorb much of the costs themselves. In addition the mothers may require extended periods of inpatient and outpatient drug abuse treatment, stays which are often not reimbursed in full by either public or private third party payors which typically only pay for 28 days of inpatient treatment.

The phenomenon of "boarder" babies has received a great deal of media attention. Although their numbers are small, they represent the total failure of our systems of care to provide needed services in timely fashion. In a study of boarder babies in New York City, inadequate housing was the explanation for 49% of the boarder babies, and maternal drug abuse accounted for 48%. A study in August 1989 of the 28 boarder babies in the District of Columbia Hospitals cited three reasons for their status: (i) Abandonment of the baby by the mother and no interest from other relatives; (ii) Although parents have failed to visit, relatives are interested but hospital staff cannot release the baby to them without parental permission which has not been obtained; (iii) Hospital staff believe the parent(s) is not able to adequately care for the baby, due to drug addiction or mental illness. Some of these babies had special medical and developmental needs requiring special post discharge care at home (Beyer, 1989).

The failure to find these babies substitute homes is largely a result of weaknesses in the child welfare system such as acute staffing shortages and high caseloads, severe shortages of foster families, and insufficient training programs for them. Inadequate coordination between the protective services, court and medical care system resulting in endless bureaucratic delays before discharge is often an additional contributing factor. In response, some hospitals are beginning to take on some child welfare functions themselves.

Since 1985 states have been reporting a steep rise in the numbers of children entering foster care. There are many factors responsible for this trend but high among them in certain areas of the country are the increasing rates of homelessness and of parental substance abuse. (See background briefing report, January 19th, 1990.) Child welfare systems in large cities are reporting that high and rising percentages of their entrants into foster care are related to parental substance abuse ranging currently from 80% in Washington D.C. to 50% in Illinois. In New York State 11.6% of those children who entered foster care in 1988 were less than one month old, and the majority of these were children of addicts. A study conducted by the Black Child Development Institute of the case records of black children who entered foster care in five cities found that parental drug abuse was a contributing factors in 36% of the placements, half of these children were under age five, their mother's mean age was 29 years, and on average, 54% were still in care 18 months later. Significantly, in this study, few concrete services had been provided to the families to help prevent the need for placement.

OVERVIEW OF FEDERAL RESPONSES

Because the needs of this population are so varied and interconnected, helping drug abusing mothers and their children involves accessing an array of services. Many Federal programs affect these families who are often low income or unemployed and in need of services such as basic food, shelter, and child care and pre-school programs for their children. The basic federal programs that fund these services are: AFDC and Medicaid, the major sources of financial support and medical care for this population; Maternal and Child Health Services Block Grants (Title V); Women, Infants and Children (WIC) nutrition program; various health services provided by the Community and Migrant Health Center program; Head Start and other pre-school child care programs. All these programs have the potential to focus specifically on the special needs of this population and some are beginning to do so.

In addition the federal child welfare program, P.L.96-272, the Adoption and Child Welfare Assistance Act of 1980 creates the legal framework for the child welfare system and funds many of the services that come into play when there is any question of child abuse and neglect and placement of these children outside of their own families. Similarly, the federal program Part H of P.L. 99-457, Education of the Handicapped Act Amendments of 1986, creates a mandate to states, and gives them the "glue" money, to provide coordinated, comprehensive family-centered early intervention services to drug-exposed babies and toddlers up to age 3 and other children who are developmentally delayed or at risk of delay. (For more details on these two programs, see Background Briefing Reports for January 19th, 1990 and March 16th, 1990.)

Preliminary evaluations of drug treatment programs for these women have shown that becoming and staying drug free may be impossible for some women unless they are able to break ties with drug abusing friends and family members through moving to a new location. Finding housing is often a major barrier in being able to do this. The most recent Federal program to help this population is the McKinney Act of 1989. The program funds demonstration projects providing innovative approaches to help homeless populations. In some cases, funds are available for child care.

In addition to these federal programs that provide basic services to low income families, in the past few years there have been several special federal initiatives designed specifically to target this population. In general, all of these programs have two main goals: **prevention and treatment services** and **child protection.** Prevention/treatment services are aimed at drug abusing expectant and postpartum mothers and their infants and children. Child protection services aim either to help the mother become a "good enough mother" through drug rehabilitation and family preservation services or place the infant or child in a temporary or permanent foster care/ adoptive home if the mother is found to be incapable of parenting.

These new initiatives include the 1986 ADAMHA Block Grant program which created a 5% set aside for women's alcohol and drug abuse services, which for FY'89 was raised to 10%, and included a special emphasis on services for pregnant and post partum women; new prevention and demonstration programs funded through the Office for Substance Abuse Prevention, the National Institute of Drug Abuse, and the Office of Human Development Services, and several new research initiatives funded largely through different agencies of the Public Health Service.

In addition two new laws passed in 1988, the Abandoned Infants Assistance Act of 1988, and the Temporary Child Care for Handicapped Children and Crisis Nurseries Program of 1986 fund demonstration programs and services for infants who are abandoned (the so-called "boarder babies') many of whom are drug-exposed or victims of AIDS or who have other disabilities that require out-of-home care.

A more complete listing of new or planned federal initiatives that focus specifically on this population is included on page 23.

Coordination at federal, state and local levels. Every discussion of services needed for this population emphasizes the critical importance of coordination at all levels. At the federal level in order to keep abreast of and coordinate all the various programs and activities relating to drug abuse in general administered by the Department of Health and Human Services, the office of the Counsel to the Secretary for Drug Abuse Policy in the DHHS was created in the Secretary's Office. Similar offices have been established in other agencies, specifically the Department of Education and the Department of Justice. All these federal coordinating offices work with the National Office of Drug Control Policy in the White House.

Recently, the DHHS Counsel has created an interagency working group to specifically monitor the programs targeted to pregnant and postpartum women and their children. The working group will try to identify gaps in services and link funding efforts between, OSAP, PHS, HDS, and the Department of Education, so that programs in the states can efficiently access money from all the available sources to mount new program initiatives. Similar coordination efforts are needed, at state and local level and are beginning to be established in some states and communities.

Proposed federal legislation:

The tragic results of drug abuse during pregnancy has caught the attention of Congress. While few Members of Congress have introduced bills specifically targeting this population a number of hearings have been held recently (see p. 19), or are currently planned, and legislation is expected to be introduced soon. A coalition of Washington based organizations concerned with the issue is pushing for legislation to increase access to treatment for substance abusing mothers and their children (see Organizational Resources p. 20). In Congress, a number of approaches and specific proposals are being discussed such as:

--expansion of Medicaid to pay for increased treatment services;
--universal testing of all newborns;
--a law to require all treatment centers to accept pregnant women;
--mandatory prison sentences for pregnant women to protect the fetus;
--laws to make it easier to terminate parental rights;
--mandatory treatment for women who give birth to a drug-exposed infant;
--increased funding for drug and alcohol treatment oriented toward women;
--voluntary sterilization of women who cannot get off crack;
--and massive public education campaigns.

Many members of Congress are reluctant to introduce legislation until it is clearer what the Federal role should be in this complex problem. Currently Senator Pete Wilson (R-CA) has introduced the only bill specifically for this population. A bill by Senator Herb Kohl (D-WI) will be introduced after the Easter recess. These two bills represent divergent philosophies about how to help this population, with Wilson proposing that stricter penalties will encourage woman to seek care and Kohl proposing that more services and outreach will help.

Senator **Pete Wilson** proposes to fund intensive and expensive treatment programs for women and their children through the "Child Abuse During Pregnancy Prevention Act " (S.1444). But the money will only be made available if the state enacts punitive legislation.

The proposal would fund five comprehensive, residential state demonstration projects at a cost of $50 million through the Office for Substance Abuse Prevention (HHS) on the condition that the states receiving grants make it a crime to give birth to an infant who is impaired by maternal

substance abuse. Prevention would be promoted by enforcing a law that says that if the expectant mother discontinues her drug use and gives birth to a healthy baby no charges will be filed. But if the baby is born chemically exposed, the crime of passing drugs via the umbilical cord would carry a sentence of 3 years mandatory rehabilitation in a custodial setting or out-patient setting under certain conditions. Efforts must be made to treat the woman with her children. If she successfully completes the program her record will be expunged. The bill is pending in the Labor and Human Resources Committee.

Senator Kohl's proposed $455 million bill, entitled "Comprehensive Drug Abuse Prevention and Treatment Act of 1990" would require a number of new initiatives and changes and budget increases in the service programs that already assist this population. This bill is likely to be referred to the Senate Finance Committee. The following are some of the major provisions in the original draft of the bill that is now being considerably revised:

- To inform women about the dangers of "crack "and other drug use during pregnancy, the draft bill sets up through the Public Health Service a new program to educate parents and the general public. The rationale for such a public education campaign is that many women do not believe that "crack" will hurt their unborn child. And many people do not understand how early in pregnancy "crack" or even alcohol can harm the fetus or how severe the effects can be.

- Several government agencies would be given grant money in the initial draft to improve treatment for populations at risk of drug abuse such as: high-risk youth, pregnant and post-partum women, Native American women, and women in prison.

- Providing increased insurance to families unable to pay for services is also a goal of the proposal. Medicaid coverage for private alcohol and drug treatment programs for women of child-bearing age would be expanded. Medicaid could also be expanded to cover 21 weeks to 9 months in a residential drug treatment setting for a women and her children. Access to SSI Disability Benefits would be expanded to help infants and children who have been disabled because of their mother's drug use during pregnancy.

- Recognizing the housing needs of many of these women, the draft bill would increase funds to HUD for public housing. Priority housing would be given to families where the lack of housing is a primary factor in imminent placement of their children into foster care.

- The draft bill would establish an interagency committee on parental substance abuse to coordinate all research and educational programs and other activities within the Department of Health and Human Services that relate to the effect of parental alcohol and drug abuse on family dysfunction and child health and welfare.

NEW MODELS OF COMPREHENSIVE PRENATAL AND POSTPARTUM TREATMENT PROGRAMS

(Sources: Chavkin, 1989; Chisum, 1990; Feig, 1990; Halfon, 1989; Hutchins, 1990; Johnson & Hutchins, 1990; Larsen, ed. 1990; Tittle & St.Claire, 1989; West, 1990)

Concern about the problem of substance abuse in pregnancy has been accompanied by a growing awareness of the lack of drug treatment services for pregnant women substance abusers. Drug treatment programs to date have basically been designed to meet the needs of heroin users who are predominantly male. Few programs are equipped to meet the medical, psychological or social needs of pregnant women, or of mothers with children. Some programs are fearful of liability if they serve pregnant women. Women who seek drug treatment in these programs are too often denied access to them. Chavkin's survey of 78 drug treatment programs in New York revealed

that 54% of them refused categorically to serve pregnant women, and 87% of them had no services available for pregnant women receiving Medicaid. Similar reports have come from other parts of the country.

The first programs specifically designed for pregnant substance abusers were based in perinatal hospital-based settings. Most of these programs grew out of the experiences and frustrations of neonatologists, pediatricians and nurses working in premature intensive care units who became determined to find ways to bring the pregnant women into prenatal care as early as possible in the hope that their drug abuse could be modified and the damage to their infants could be prevented. In some communities special programs have been established as an offshoot of child protective services, providing intensive family based services to drug using and other troubled mothers that would prevent the need for placement.

There are several cross cutting issues that every successful program for pregnant addicts has had to try and address, namely the issues of adequacy, access, outreach and staff training.

Adequacy and access. In all three major service systems there is a severe shortage of services and existing services are underfunded. Hospitals do not have the staff and equipment to deal with the problem adequately. The foster care system is understaffed, there are not enough foster homes, nor enough family preservation services to help keep the families together. Drug treatment centers often won't treat pregnant women or won't accept Medicaid which a majority of these women use. Generally these women do not have access to child care and most of these women have other children at home.

Outreach. But even when there are sufficient services---and in some places there are a lot of services available---drug abusing pregnant women and young mothers are often hard to enrol and retain in treatment. There are several reasons for this. First, there are numerous logistical reasons. The women often live in areas far from the treatment programs and have no transportation, no telephones, are fearful to leave the house because of the violence in their neighborhoods and in general lead disorganized lives which makes it difficult for them to keep appointments. These factors also make it very difficult for program staff to make home visits. Second are motivational factors. "Crack" often appears to suppress the maternal instinct which often provides the major incentive to women to get off drugs. Alternatively some women are said to avoid prenatal and other treatment programs for fear of being prosecuted and/or losing their children.

Training. Many health care and social service professionals are not trained to recognize the warning symptoms of substance abuse or adequately assess the type or degree of substance abuse. Thus there are problems with initial identification of drug abuse even when the pregnant women do seek prenatal care. Many doctors do not routinely test pregnant mothers for drugs or the newborn for drug exposure, especially if the baby is born to a white middle class mother. In addition, professionals trained in one discipline and working in one system have difficult understanding the assumptions, terminology protocols and service approaches of those from other disciplines and other systems.

In 1986 only a handful of these special programs existed across the country. None have been evaluated sufficiently to assess how successful they are with this very difficult population. Nevertheless a considerable amount of clinical experience has accumulated and led to some agreement on the basic components of a comprehensive program model. Since 1986 the Office of Substance Abuse Prevention, NIDA and the Children's Bureau have funded a number of model demonstration programs for pregnant and post partum substance abusers and their children which to a greater or lesser degree attempt to be comprehensive.

Continuum of Care Components: Comprehensive programs attempt to provide, directly or by referral, a continuum of inpatient, residential, day treatment and outpatient services for mother

and child that can include prenatal medical care, pediatric "early intervention" services (medical, developmental and psychological), social services case management, chemical dependency treatment, parent education and training and mother/infant counseling, child care, drop-in centers, support groups, hot lines, and drug free residential options. In order to bring the women into these services outreach activities including home visits are common, and transportation often needs to be provided.

One striking omission in most descriptions of comprehensive programs is any mention of helping these women with the difficulties in their relationships with their husbands or male sexual partners.

A diagram illustrating the components of the continuum of care that one of these programs believes needs to be provided to chemically dependent women is included as page 31. (Halfon, 1989).

Key model program principles and strategies. In addition to the individual service components illustrated in the diagram certain key principles and strategies are commonly mentioned as necessary elements of successful programs. These are:

- *The program must be family-focused* with some services designed to focus on the needs of the mother as a woman, others to focus on the medical and developmental needs of the child, and others to focus on the mother-child relationship. Even in situations where it is necessary to remove her child from her care, at least temporarily, the mother still needs services both to help her regain her child or release him or her for adoption, and/or to prevent her from giving birth to additional drug-exposed children.

- *Programs must operate with a broad definition of family*. Quite frequently relatives, usually the grandmother, shares responsibility for the child, or will take over the care totally when the mother is incapable of doing so. These caretaking relatives need to be involved in services to help the mother and child. Husbands, men living with the mother and the fathers of their babies may also need to be involved.

- *Services also need to be provided for foster parents* both to enable them to meet the special needs of drug exposed babies and children and to help encourage mutually supportive relationships between the biological parent(s) and foster parent. (Child welfare agency practice has usually been to not permit direct contact between the biological and foster parent, thus often discouraging the parent from visiting and maintaining an interest in her baby.)

- *Programs must be flexible to offer a range of levels of intensity of services* since not all mothers are as seriously troubled or as needy as others.

- *There must be close coordination between the different agencies and service systems* involved with this population , namely health care, protective services, social services and the courts. Some communities have accomplished this through establishing community coordinating councils with broad representation from a range of services which hammer out various interservice agreements etc. The lead program must develop good liaisons with community agencies who provide concrete services such as employment and training and housing services to which the mothers can be referred.

- *Access to services must be simplified.* As was pointed out at a congressional hearing, an engineer's degree is virtually needed to access and use all the multiple services drug abusing mothers and their children require. Thus a highly desirable program model is the "one stop" services center, where many services are located under one roof.

- *Programs should include both home-based and center-based components*. Home-based components are needed to help make a thorough assessment of the patterns of substance abuse

and the relative risk to the child; explore the resources available within the extended family and community; and develop supportive relationships with these resources. Center-based components are needed to draw these women out of their social isolation, to introduce structure and routine into their lives, provide peer support and a familiar and secure place to turn to in times of trouble.

- *Traditional addiction treatment services need to be modified to meet the needs and child care responsibilities of chemically addicted mothers,* and to take account of the fact that many live in communities that are drug ridden. Some believe this implies less emphasis on the disease model and goal of total abstinence, and a more realistic acceptance of the tendency to relapse.

- *It is very important to train multi-disciplinary professionals working in these programs together as a team.* They need to improve their knowledge of the complex medical, social, legal and ethical issues involved in caring for substance abusing mothers and their children, and develop a common language, perspective, and goals so they can plan and carry out coordinated interventions.

Program Evaluation and Cost Effectiveness

Since most of these model demonstration programs are still very new there is, as noted, no strong research evidence available as yet about their effectiveness. Until recently few treatment programs have been provided funds for evaluation. Nor is there general agreement on what outcomes are most important to measure since this depends largely on the program's specific goals and perspective. For example, those health oriented programs which focus prenatal services on the pregnant mother are clearly most interested in assuring the health and well-being of the baby. Other programs may believe that avoidance of placement of the child is the most important goal. Some programs make abstinence from drugs a condition of the mother's participation, others may think it is more important that the mother continue to participate in the program than that she be totally drug free and can accept a certain number of relapses.

Moreover the whole issue of what kinds of evaluation designs are feasible is still being developed. The ten demonstration models recently funded by NIDA all include an experimental design with various kinds of comparison groups and control groups and are expected to yield the most useful information on program outcomes to date. The demonstration programs funded by OSAP are all expected to conduct a program evaluation. While these must follow some broad parameters, the evaluation designs are individually tailored to the particular program. A few of these demonstrations are choosing an experimental design with control groups. Currently there are no multi-site demonstrations or plans for cross-site evaluations such as have been so useful in other policy areas such as the work/welfare state demonstration programs.

Another important issue that is of particular interest to policymakers, is the question of cost effectiveness, yet no evaluations to date have been designed to specifically address this issue. Many clinicians experienced with this population believe that substance abusing pregnant women and mothers can only be helped through initial involvement in an inpatient and/ or residential programs. However these programs are very costly and serve relatively few in number. Other clinicians believe it is possible to help many, though not all, substance abusing mothers through intensive day treatment programs with built in outreach services which can serve many more women effectively at considerably lower cost.

EXAMPLES OF FOUR MODEL DEMONSTRATION PROGRAMS

Brief descriptions of four model demonstration programs are provided here to illustrate the range of settings and types of services provided.

Families First is a family preservation program administered by the Office of Children and Youth Services, Department of Social Services in Michigan. It began in 1988. It operates in eighteen of 83 Michigan counties, and is funded largely with state dollars. Referrals come from the child protective services unit. The program is based on the Homebuilders model, a family preservation program pioneered in Washington state and now being implemented in dozens of sites across the country.

Intensive, out-patient services are provided for a period of 4-6 weeks to families in which at least one child is a imminent risk of removal. Generally each family receives between 5-20 hours of services per week provided directly in their home. Services focus on changing specific behaviors. While the program is not designed specifically for substance abusing mothers, drug abuse is a major factor in the lives of 50-60% of the families served. 48% of the families served are minorities, 41% black. In the first year 970 families, and 2,505 children were served statewide. Although a formal evaluation of the program is only just underway, program statistics to date indicate that an 80% success rate in averting placement at the one year follow up. Of those families where substance abuse is a major problem, approximately 75% of the children are able to remain with their mothers, and less than 5% are placed in foster care. The others are placed with relatives.

Key features of the program specifically related to the problem of substance abuse are: thorough assessment of the degree of substance abuse; special techniques, building on extended family and neighborhood resources, to structure the safety and care of the children including in emergency "bottoming out" periods; development of a plan for getting the mother to enroll in drug treatment and taking the first steps with her. In addition the family preservation staff work with the mother to increase her self esteem, decrease her isolation, strengthen her social support network and help her access needed concrete services.

Contact: Susan Kelly, Director, Families First, Office of Children and Youth Services, 300 South Capitol Avenue, P.O. Box 30037, Lansing, MI 48909 517/373-3465

Operation PAR (Parental Awareness and Responsibility), located in St. Petersburg, Florida, is one of the most successful comprehensive programs to date for drug abusing women and their infants. PAR has provided residential care for substance abusing pregnant women since 1971. In 1988, PAR established an OSAP-funded Child Development and Family Guidance Center to address the developmental needs of children affected by maternal substance abuse.

The program serves 100 women, 65% black and 35% other (very few are Hispanic). The program accepts children. In the long-term residential program, children from ranging from infants to 10 year olds, may live with the mother while she is being treated. In the out-patient setting children age 2 to 5 years are cared for in child care. The program's services are coordinated with the local health department, local hospital pediatrics departments, child protection teams, the local juvenile court, and drug treatment systems. Outreach activities are performed through the church, Head Start, Child Protective Services, the State's attorney's office, and the children's hospital.

Although the program has been in existence for 20 years, it has only recently received funds for evaluation of its treatment program. Recently NIDA has begun a five year evaluation of PAR which will examine the effectiveness of treatment. The only evaluation PAR has to testify to its success, is an independent evaluation conducted by the Florida State Department of Corrections. The Department looked at the rearrest rates of women that they had referred to PAR after 10 years. Seventy seven percent had not been rearrested.

Contact: Shirley Coletti, Operation PAR, Inc., 10901 C Roosevelt Blvd., Suite 1000, St. Petersburg, FL 33716. (813) 570-5080.

The Coalition on Addiction, Pregnancy and Parenting (CAPP), is a new program funded by OSAP, to provide technical assistance and evaluation to two residential homes for women in Massachusetts and to encourage other residential homes to take in substance abusing women. **Contact:** Norma Finkelstein or P.J. Tone, CAPP 349 Broadway, Cambridge, MA 02139. (617) 661- 4093.

One of the homes CAPP assists is, **New Day,** a 10 bed residential program for pregnant, substance abusing mothers and their children in Cambridge, Massachusetts funded by the state Department of Public Health. The program provides residential care for 9 months to a year to substance abusing mothers and their infants and provides a continuum of care for women before, during and after their pregnancy. It's clients are 50% black, 40% white, and 10% Hispanic. The first evaluation of the success of women attending this program will be conducted by CAPP which also provides New Day with a child development specialist who conducts a parenting skills workshops once a week.

Contact: Eileen Brigandi, New Day, 242 Highland Ave., Summerville, MA 20143 (617) 628-8188.

SHIELDS for Families project in Compton CA, near Los Angeles, provides a flexible continuum of non-residential programs for drug/alcohol abusing women, their drug-exposed newborns, and their high risk siblings. All the programs to date are non-residential. The reasons for this are financial, pragmatic and philosophical. Many more mothers and children can be served in the day treatment and outpatient programs than in a residential program, and efforts to keep the children in the home are usually highly cost effective compared with the costs of caring for infants and children placed in small group homes or foster care. The basic orientation of the program is the belief that with the majority of substance abusing mothers, it is possible to work towards family maintenance and prevention of the birth of additional drug exposed babies on an outpatient basis. Only about 30% of drug abusing pregnant women and mothers, they believe, require a period of residential treatment. Random drug testing continues throughout the program but drug relapses are expected, and the only cause for termination from the program is total-nonparticipation.

The program is affiliated with the Drew Medical Center, Department of Pediatrics and all the infants are involved in the clinic's High Risk Infant Follow Up Program. There are three programs (with a fourth about to open) which offer services of varying levels of intensity carefully tailored to a thorough assessment of the mothers' and infants needs. Services offered include home visits, group counselling, therapeutic infant day care and an intensive, structured therapeutic recovery and family building program focussing intensively on the mother's cocaine abuse which can last for up to three years. One program provides a short term crisis intervention and respite child care program to prevent child abuse and neglect and removal of the child from the family. An additional component is an afterschool drug/alcohol prevention program for the children ages 7-15 of the SHIELDS project participants.

SHIELDS is a founding member of the Council on Perinatal Substance Abuse of Los Angeles County. This coalition was started in 1985 as a result of a group of concerned professionals who saw the need for multi-disciplinary coordination and mutual education. Council members meet monthly and work on developing a common language and protocols, cross education and training and activities to advocate for improved services to this population.

Contact: Kathleen West, Director, Program Development, Research and Evaluation, The SHIELDS for Families Project, 2115 N. Wilmington Avenue, Compton, CA 90222. 213/605-0650 or 0651.

LEGAL ISSUES

(Sources: Connolly & Marshall, 1990; Larsen, 1990; Wiet, 1990)

The courts and state legislatures are only beginning to grapple with a number of difficult legal issues that arise from the use of drugs by pregnant women and mothers of young children. Meanwhile health professionals and child welfare workers are having to make judgements and decisions every day within the ambiguous, conflicting and evolving framework of constitutional rights, tort and criminal law and existing federal and state laws regarding confidentiality in health care, child abuse and neglect and so forth. State child abuse laws for example, although operating within the broad mandates of federal law, are very vague about what constitutes evidence of child abuse and neglect. Most of the issues involve a delicate balancing of children's rights and interests with maternal rights to privacy and parental autonomy.

Another major difficulty for service professionals is that not only do state laws vary but different jurisdictions within states, and various judges within jurisdictions may handle these cases and issues very differently.

Professionals working in different systems have different goals and perspectives. For example, health care professionals are often opposed to mandated testing or child abuse reporting requirements which they are convinced serve as a deterrent to pregnant womens' seeking health care. However there is no research available about whether mandatory testing and reporting and punitive sanctions do have a deterrent effect on pregnant women seeking treatment. Court personnel involved in child abuse and neglect cases may welcome universal testing requirements, mandatory reporting etc. in order to require that mothers become involved in treatment.

It is important to note that reports to child protective services of positive test results generally do not, by themselves, give the court jurisdiction over the family or lead to criminal prosecution. However what happens after a report varies considerably depending on the state, locale and agency practice. Most often it simply initiates a social services investigation which may lead to a child abuse and neglect or abandonment petition but may result in the case being dismissed or the family put under supervision.

Due to these different professional and system perspectives, and the lack of definitive guidance from courts or in the law, interagency cooperation and collaboration is extremely important in order to resolve how to handle these issues expeditiously on an operational basis.

Some of the difficult legal and ethical questions and issues being wrestled with are:

--Should all pregnant mothers be tested routinely, or only when there is evidence of substance abuse? Does mandatory testing interfere with a mother's right to privacy?

--Should mothers have to give their consent to being tested themselves? Is parental consent needed to test the newborn?

--Does maternal substance abuse during pregnancy constitute evidence, ipso facto, of child abuse?

--Is information about maternal drug abuse, clearly exempted, under child abuse statutes, from the overarching presumption of patient confidentiality established in federal law?

--Should test results confirming substance abuse in the mother and/or infant be required to be reported to child protective services?

--Judges are usually reluctant to agree that a drug-exposed infant should be released from hospital straight into foster care unless assured that "reasonable efforts" have been made to keep the family

together. But the problem is that many communities do not have services available to help these mothers and their families. In such cases should the child be removed?

--Under what circumstances does parental substance abuse justify or require the termination of parental rights, and subsequent adoption? Is termination made too difficult?

Courts have generally not considered an unborn fetus a child for purposes of state abuse and neglect statutes and New Jersey is the only state legislature that has passed a child abuse and neglect statute that extends to unborn fetuses. However several courts have been willing to order a pregnant woman to submit to medical treatment for the benefit of the fetus she is carrying.

There have been, and continue to be attempts to criminally prosecute mothers for their substance abuse. Several court decisions related to this topic have hit the media headlines. Among the most notorious are a case in July 1989 when a judge in Seminole, Florida found a mother guilty of two felony counts of delivering a drug to a minor, when she, a cocaine addict, passed the drug on to her two children through the umbilical cord in the few seconds after their birth before the cords were severed. In another case in June 1988 a judge in D.C. ordered a pregnant mother, convicted of a second-degree theft to serve out her time in jail instead of on probation on the grounds that the fetus needed protection from her alleged drug use.

In spite of a few isolated decisions to the contrary, the courts and legislatures have basically steered clear of criminalization of the issue. But a report of the findings of an ABA study of professionals interviewed across Washington state suggests that there may be a growing sentiment for extending involuntary civil commitment for treatment to pregnant women, similar to programs for treating alcoholics (Larsen, ed. 1990).

STATE POLICY RESPONSES

There is very little information available to date about how the states overall are responding to the service needs of pregnant and post -partum substance abusers, nor how the state are spending the ADAMHA block grant set-asides for this population. A recent survey by the National Association of State Alcohol and Drug Abuse Directors (NASADAD) of the member states' services provided to women in 1989 reported that less than 30,000 pregnant women received alcohol and drug treatment services compared with the estimated 234, 662 needing treatment. And only 20.6% of the total expenditures on treatment services was spent specifically on women's programs.

This survey asked the states to report on any special alcohol and drug treatment programs they funded in the state for this population. From this survey it is clear that some states have forged ahead and established a number of programs. States which identified at least six such programs are Colorado, Connecticut, Florida, Illinois and Missouri. (Note: other states may have demonstration programs funded directly from other federal agencies and through the state ADASA agency or they have family preservation programs administered by the child welfare system, such as in Michigan, which provide some services to large numbers of substance abusing mothers.)

Brief descriptions of two of these states' responses, Illinois and Florida, will be given here:

Illinois: State public officials became concerned about the growing drug problem among pregnant women and mothers when they noticed in 1986 that the infant mortality rate began to rise again in Illinois after a long period of decline. By 1988, hospitals throughout Chicago were reporting that 10-40% of the infants being delivered in the inner city had been exposed to cocaine during pregnancy. And drug related child abuse and neglect reports were also climbing. It became

clear that one of the major problems was a lack of knowledge about the problem of substance abuse in pregnancy on the part of both professionals and the public at large.

Illinois' response was to plan a collaborative and innovative education, prevention, and referral intervention strategy whose lynch-pin was inter-agency cooperation and coordination. The model is a collaboration of the Illinois Department of Children and Family Services, the Department of Alcoholism and Substance Abuse and the National Association for Perinatal Addiction, Research and Education (NAPARE) (see Organizational Resources, p. 20).

The basic components of this new initiative are: a toll free cocaine baby helpline reaching five mid-western states with information and referral; training for over 2,000 medical, social service and substance abuse professionals to recognize, refer and treat cocaine affected infants; developing a national newsletter; sponsoring three national training conferences; and providing integrated medical, substance abuse and social services to over 400 mothers and infants in two treatment programs, Project Futures and at Northwestern Memorial Hospital.

Contact: Cassie Schultz, NAPARE, 11, E. Hubbard Street, Suite 200, Chicago, Illinois 60611 312/329-2512.

Florida: The state of Florida's Drug and Alcohol Abuse Administration responded quickly to the new federal mandates to increase and improve substance abuse services for pregnant women. In October 1989 the plan for providing a comprehensive continuum of care for pregnant substance abusing women in every district was put into operation. The goals of this initiative are to:

--Assist the woman in achieving a drug-free life style;
--Reduce the incidence of drug-exposed newborns;
--Improve access to health, prenatal, maternal and well-baby care;
--Provide a program of economic rehabilitation;
--Prevent the spread of AIDS;
--Reduce the incidence of legal involvement;
--Assist the woman in meeting basic life needs for food, clothing shelter etc.

Currently there are 19 programs offering the full range of services and 17 which offer some portion of the total package. The goal is to serve 1500 women and their children per year. These new initiatives are specialized programs offered by existing free-standing substance abuse, or occasionally mental health, agencies and are funded through the ADAMHA block grant set asides.

The package of services includes residential, day treatment and after care services, training in life management skills, vocational/education services and developmental child care provided in house or by contract. The treatment offered includes individual, group and couples/family counseling with particular emphasis on assuring good prenatal care, parenting skills, behavioral change and developing a drug free life style. Program staff provide community education and outreach to get the women into treatment and build strong linkages with a wide range of medical and social agencies. The model package is based to some degree on the experience of the well known Operation PAR program's experience of serving pregnant substance abusing women.

The services the women receive will be carefully charted by the Drug and Alcohol agency's internal management information system, CODAP. In addition the state has contracted with Dr Chasnoff of NAPARE to conduct a study of substance abusing women who sought treatment during their pregnancy compared with those who did not.

Contact: Terri Goens, Health and Rehabilitative Services, Alcohol and Drug Abuse Administration, Bldg. 6, Room 182, 1317 Winewood Blvd, Tallahassee, FL 32301 904/488-0900

HEARINGS ON SUBSTANCE ABUSING MOTHERS AND THEIR INFANTS
101ST CONGRESS • 1989-1990

SENATE

Senate Labor and Human Resources Committee,
Subcommittee on Children, Families, Drugs, and Alcoholism

October 9, 1989 Field hearing in Indianapolis, IN *"Drugs and Babies: What can be done?"*

February 5, 1990 *"The Impact of Substance Abuse on Children in New York City"*

March 8, 1990 *"Falling Through the Crack: The Impact of Drug-Exposed Children on the Child Welfare System."*

Contact : Patty Cole

Senate Finance Committee

Hearings have not yet been scheduled, but the committee is planning an overview of the issue and how it will affect foster care, child welfare services and Medicaid programs which the committee has jurisdiction over.

Contact : Margaret Malone

Senate Governmental Affairs

The committee is planning a hearing on how federal agencies are coping with administering new money for drug treatment programs.

July 31, 1989 *"Missing Links: Coordinating Federal Drug Policy for Women, Infants and Children"*

Contact : Marsha Renwaz

HOUSE OF REPRESENTATIVES

The Ways and Means Committee
Subcommittee on Human Resources

April 3, 1990, *Field hearing: D.C. General and Children's Hospital*

April 4, 5, 1990 *"Federally Funded Child Welfare Foster Care and Adoption Assistance"*

Contact : Debra Colton

Government Operations Committee

The committee is conducting oversight hearings on the National Drug Control Strategy

April 3, 1990 *"National Drug Control Strategy: Prevention and Education Strategies"*

April 17, 1990 *"National Drug Control Strategy: Drug Treatment Programs"*

Contact: Carol Bergman

Select Committee on Children, Youth, and Families

April 17, 1989 *"Born Hooked: Confronting the Impact of Perinatal Substance Abuse"*

April 19, 1990 *"Beyond the Stereotypes: Women Addiction, and Prenatal Substance Abuse"*

April 23, 1990 A field hearing in Detroit, MI *"Getting Straight: Overcoming Treatment Barriers for Addicted Women and Their Children"*

Contact : May Kennedy

ORGANIZATIONAL RESOURCES

A number of national organizations are becoming concerned about this issue and have sponsored special meetings and conferences to educate their members and others about the problem of perinatal substance abuse. Conferences or special meetings have been recently held by the National Center for Clinical Infant Programs, Child Welfare League of America, the National Forum on the Future of Children, National Academy of Sciences and the National Academy of Medicine. The following is a list of organizations that have taken a special interest in this topic and can provide resources to others.

The Coalition on Alcohol and Drug Dependent Women and Their Children.

Brought together around the contention that pregnant women should be treated for their alcohol and drug abuse problems rather than punished, The Coalition on Alcohol and Drug Dependent Women and Their Children was formed in May of 1989 to lobby Congress and educate the public about the need to improve access to treatment services for women. The group is comprised of organizations representing women's health, legal issues, civil rights, child welfare, alcohol and drug problems, and maternal and child health providers.

The Coalition's work is done through several committees: the **Public Policy/Legal Issues Committee** has drafted proposals for enhancing a number of federal programs which directly and indirectly serve alcohol and drug dependent women and their children; the **Treatment Services Committee** is in the process of conducting an extensive survey of the first 25 OSAP funded demonstration programs; the **Prevention/Education Committee** has compiled and mailed a comprehensive education packet for caregivers on alcohol and drug related birth defects to over 2,500 caregivers across the country. Two ad-hoc committees are exploring Medicaid reimbursement procedures and liability issues for service providers.

Contact: Susan Galbraith, Coordinator, (202) 483-4909 or Christine Lubinski, (202) 737-8122 or write The Coalition, c/o NCADD, 1511 K Street, NW, Suite 926, Washington, D.C. 20005.

Center on Children and the Law, American Bar Association.

The Center on Children and the Law (formerly the National Resource Center on Child Advocacy and Protection) is currently involved in a number of activities directed at the growing problem of parental substance abuse. This includes a study undertaken for the State of Washington to evaluate the adequacy of the state's laws related to this topic and the publication of a report on the responses of the legal, medical and child protection systems to the problem of drug-exposed infants and their families. The Center has recently published a report on legal issues involved in systems providing coordinated responses for drug-exposed infants and their families (Larsen, ed. 1989).

The Center is currently developing, under a grant from the State Justice Institute, a training curriculum on handling cases involving parental substance abuse for juvenile and family court judges.

Contact: Robert Horowitz, ABA Center on Children and the Law, 1800 M Street N.W., Suite 200S, Washington, DC 20036 202/331-2250

March of Dimes Foundation

The March of Dimes is a national research and education foundation dedicated to the prevention of birth defects and improving the outcome of pregnancy. It is funding 16 programs at a cost of $382,500 in 1990 to deliver services and train professionals to deal with the problem of substance abusing women and their infants throughout the country.

For more information, contact the March of Dimes, 56 Lafayette Ave, White Plains, NY 10603, (914) 949-7166.

National Association for Perinatal Addiction Research and Education (NAPARE)

NAPARE was founded in 1987 in response to a growing awareness among clinicians, researchers, social service professionals, educators and attorneys that there was an acute need for an interdisciplinary forum to address a very complex and growing problem: perinatal addiction and the long term outlook for drug-exposed children. The Association's activities include sponsoring national conferences, designing training workshops, conducting research and, with a grant from OSAP, developing a curriculum for physicians. Information packets about the problems of perinatal substance abuse are available for professionals and the public.

Ira J. Chasnoff, M.D., is the president and co-founder of NAPARE.

Contact: William Lawless, NAPARE, 11 E. Hubbard Street, Suite 200, Chicago, Illinois, 60611 312/329-2512

National Clearinghouse for Alcohol and Drug Information (NCADI)

NCADI provides information to the public and professionals about the effects of using drugs and alcohol during pregnancy. Reading material, films and videos are available at low cost or no cost to any organization wishing to educate its staff or the public about this problem.

For more information, the National Clearinghouse for Alcohol and Drug Information (NCADI), P.O. Box 2345, Rockville, MD 20852 (303) 468-2600.

The National Council on Alcoholism and Drug Dependence, Inc. provides education on alcoholism and other drug addiction; offers prevention programs for schools; and answers questions from the public. NCADD sponsors National Alcohol Awareness Month in April and National Alcohol-Related Birth Defects Awareness Week beginning on Mother's Day each year.

For more information, contact The National Council on Alcoholism and Drug Dependence, Inc., 12 W. 21st Street, New York, NY 10010, (212) 206-6770 or the Washington office, 1511 K Street, NW, Suite 926, Washington, DC 20005, (202) 737-8122.

Twentieth Century Fund, Drug Abuse Development Project

At the request of five national foundations---Conrad Hilton, Nathan Cummings, Ford, Rockefeller and Pew Charitable Trust---the Twentieth Century Fund is engaged in a planning project to explore and propose a strategy for a foundation sponsored initiative assisting program development in the war against drugs. Three areas of activity will be explored: prevention/education; treatment and

enforcement/criminal justice. This project is especially interested in the need for increased knowledge about the effectiveness of various treatment strategies. The treatment of substance abusing pregnant women and their babies is one of its priority areas. It is expected that the recommendations from this planning study will propose a substantial commitment of national private philanthropic support to be matched with public sector funding. A report is expected to be available during the summer 1990.

The project is directed by William J. Grinker, recently head of the New York City's Human Resources Administration and the first President of the Manpower Demonstration Research Corporation. Eddie N. Williams, president of the Joint Center on Political Studies is chairman of the the project 's national advisory committee.

Contact: William Grinker, Project Director, The Twentieth Century Fund, 41, East 70th Street, New York, N.Y. 10021 212/535-4441.

RECENT DHHS INITIATIVES AFFECTING SUBSTANCE ABUSING PREGNANT WOMAN AND DRUG EXPOSED INFANTS AND CHILDREN

(Sources: Feig, 1989;)

OFFICE OF TREATMENT IMPROVEMENT (OTI), ADAMHA, Public Health Service.

Alcohol, Drug Abuse and Mental Health Block Grant. Funds in this program are passed to the states which use the money to provide alcohol, drug abuse and mental health treatment services to target populations and for specific purposes. In FY'86 Congress designated a 5% set-aside within this block grant for women's alcohol and drug abuse services. The set aside was raised to 10% in FY'89 and statutory language added an emphasis on programs for pregnant women and women with dependent children. States used the broad women's set aside for a variety of purposes, including outreach, prevention, treatment, and staff development aimed at women. Because the pregnant women and mothers emphasis is new, it is unclear at this time how states are using these funds. In FY '90 the set-aside totals $119.3 million.

The block grants are administered by the Office of Treatment Improvement, a new office in ADAMHA which was established in October 1989 to conduct a variety of activities designed to improve alcohol, drug abuse and mental health treatment services and administer the new federal drug abuse funding initiatives.

OFFICE FOR SUBSTANCE ABUSE PREVENTION (OSAP), ADAMHA/PHS.

Pregnant and Postpartum Women and Their Infants Demonstration Grant Program Authorized in the 1988 drug bill, this program is funded jointly by the Office for Substance Abuse Prevention (OSAP) and the Office of Maternal and Child Health (MCH). It is administered by OSAP. The program funded 45 projects in FY'89. These grants are for projects addressing prevention, education and treatment of pregnant and postpartum substance abusers and their children. Successful applicants were comprehensive, community based programs operated by private sector organizations (profit and not-for-profit) and government entities. The grants average $250,000 per year for 3 - 5 years. The total FY'89 appropriation for the program was $4.5 million initially and then expanded to $10 million. In FY'90 the program will spend at least $10 million but there may be more monies depending upon appropriations. Contacts: Raoul Cuervo-Rubio, M.D. at OSAP 301/ 443-0365, 0353 and Ellen Hutchins, M.S.W. at MCH, 301/443-5720.

This program is one of two main initiatives of the Division of Demonstration and Evaluation within OSAP. The other is the High Risk Youth Demonstration Grants program. Both of these initiatives receive a variety of supportive and supplementary services as follows:

o The National Learning Community. The NLC was established as a mechanism for promoting networking and information dissemination between the demonstration projects and the community of professionals generally involved in the prevention and treatment of alcohol and other drug abuse. An NLC annual conference is held in Washington D.C. and other smaller meetings and workshops are held on specific issues. In addition resource materials are prepared for the programs continuing information on "best practices" and a quarterly newsletter *Drug Abuse Update* keeps the grantees informed of recent developments in the field.

o OSAP Technical Assistance and Evaluation Support. Technical assistance to grantees is provided on request to help with program implementation, administrative issues, recruiting, training and retention of staff, developing program management information and program evaluation through the National Prevention Evaluation Resource Network.

o OSAP National Training System The Division is developing a system of continuing education for medical professionals and community program operators on drug issues. While the system is comprehensive, later separate task orders may focus on issues like perinatal drug exposure. OSAP will spend $8 million over the next 3 years developing this system.

NATIONAL INSTITUTE FOR DRUG ABUSE (NIDA), ADAMHA

NIDA Research Demonstration Grants on Drug Treatment. Authorized in the 1988 Anti -Drug Act, treatment for pregnant and postpartum women was cited as an area of national significance. Nine research demonstration projects providing comprehensive services to pregnant women were funded in FY'89 for a total of nearly $6.5 million. The projects are funded for years. An additional number of projects are expected to be funded in FY' 90.

NIDA General Research Funds. A variety of studies are being conducted with NIDA funding which involve infants and pregnant drug abusers either directly or indirectly. Among the topics being studied are the effects of drugs on the fetus, long term studies of the impacts of prenatal cocaine exposure on children, and epidemiological studies of the extent and nature of drug use among pregnant women.

NIDA Conferences Regarding Pregnant Addicts. NIDA will sponsor two conferences in the summer of 1990 addressing research findings and methodological issues relating to pregnant addicts. The audience for both meetings will be clinical and pre-clinical researchers.

Health Professions Education Program. NIDA and NIAAA jointly sponsor a clinical training grant program in alcohol and drug abuse issues. The program was authorized for $2 million in the Omnibus Drug Abuse Act of 1988.

BUREAU OF HEALTH CARE DELIVERY ASSISTANCE, Health Resources and Services Administration (HRSA)/ PHS.

The Community and Migrant Health Center Program. Operated by the Bureau of Health Care Delivery Assistance this program has three elements, described below. The Centers serve primarily women and children, and they see large numbers of substance abusers and their families among their clients:

Health Care for the Homeless Program: $60 million in each of FY'89 and FY'90 funded 109 community based organizations which provide primary health care and substance abuse treatment to homeless individuals and families. 15% of the 231,000 served were children age 0 - 14.

Substance Abuse Initiative: $3.8 million provided supplemental funding to 43 community health centers in FY89. The goal of this program is to integrate the special service needs of substance abusers. Activities include direct service provision, as well as training and curriculum development for service providers.

Comprehensive Perinatal Care Initiative: $20 million in each FY88 and FY90 provided supplemental funding to 200 community based health centers to provide care to pregnant women and young children. Some of these funds were used to provide substance abuse treatment and outreach.

Pediatric AIDS Health Care Demonstration Grant Program. HRSA operates this demonstration grants program which provided funding for 13 projects in FY88 totalling $4.435 million. No information is available yet on the FY89 cycle.

BUREAU OF MATERNAL AND CHILD HEALTH AND RESOURCE DEVELOPMENT (MCH)/ HRSA

Special Projects of Regional and National Significance (SPRANS). These demonstration grants fund a variety of programs to improve maternal, infant and child health including projects to reduce infant mortality rates, improve prenatal care, and the outcomes of teenage pregnancy and other high risk infants. Pregnant substance abusers have not yet been made a priority but are clearly served in many of the projects. Funding for the total program is projected at $7.6 million for both FY'90 and FY'91.

OFFICE OF HUMAN DEVELOPMENT SERVICES (OHDS)

The National Center on Child Abuse and Neglect (NCCAN)/ACYF. The Center, which has recently moved from it's former home in the Children's Bureau to become a separate office within the Administration for Children Youth and Families, (ACYF) is funding four demonstration projects aimed at preventing child abuse and neglect among drug involved mothers. The projects provide parenting skills training and support groups, vocational counseling, drug/alcohol rehabilitation, and social and psychological support. The projects were funded for three years beginning in FY'87 for a total cost of $1.2 million.

ADMINISTRATION FOR CHILDREN, YOUTH AND FAMILIES (ACYF)/OHDS

The Temporary Care for Children with Disabilities and Crisis Nurseries Program. Authorized under the Temporary Child Care for Handicapped Children and Crisis Nurseries Act, this demonstration grants program, administered by the Children's Bureau (ACYF) was enacted in 1986 to serve abused and neglected infants and young children, some of whom are from drug involved families. Thirty four projects are being funded (16 in FY'88 and 18 in FY' 89) for a total of $5 million. Four of the FY'88 projects focus specifically on drug addicted babies, and three serve HIV+ children.

Head Start Bureau, ACYF. Head Start is a comprehensive child development program which serves approximately 450,000 low income pre-school children. Head Start staff recognize that substance abuse is a growing problem among the families they serve, and estimate that at least 20% of children in the program have a parent or guardian with substance abuse problems. Head Start has proposed new initiatives to address the issue, including additional staff training and the development of curricula aimed at preventing substance abuse. Several programs serving HIV+ children are being funded as Head Start Innovative Projects.

Comprehensive Child Development Centers, ACYF. A new program in its first year of operation, these centers are intended to provide intensive, comprehensive, integrated, and continuous supportive services for infants, toddlers and preschoolers from low income families to enhance their intellectual, social, emotional and physical development and provide support to their parents and other family members. Most of the 22 centers include drug treatment for parents in their portfolio of available services.

HDS Discretionary Grants Program. HDS sponsors demonstration projects pertaining to the programs they administer. The issue of crack babies is slated to be among their funding

priorities in FY'90. Projects already funded from this source include four projects administered by the Children's Bureau which provide foster care, respite care, and/or case management services to HIV+ children, most of whom are born to substance abusing parents. The four are just beginning their second year and are each funded at $200K/year for 3 years.

Abandoned Infants Assistance Demonstration Grants Program. In 1988 Congress passed legislation to authorize the use of up to $10 million to meet the needs of boarder babies, including efforts to prevent abandonment, support services for abandoned infants, and capacity building efforts to help hospitals, child welfare agencies, and others better serve these children. The program was not funded in FY'89 but has received $9 million in FY'90. It is administered by the Children's Bureau.

ADMINISTRATION FOR DEVELOPMENTAL DISABILITIES (ADD)/OHDS.

University Affiliated Projects. The Administration of Developmental Disabilities maintains relationships with a number of universities for the purposes of providing interdisciplinary training for persons concerned with developmental disabilities, demonstrating exemplary services, providing technical assistance, and disseminating information. Currently five universities are providing services to drug exposed children under the auspices of this program. The services include data collection, prevention of developmental disabilities, and early intervention.

OHDS/MCH Joint Conference Regarding Substance Exposed Children These two agencies will jointly sponsor a conference, most likely to take place in the Fall of 1990, to discuss the service needs of this population. More specific information is not yet available.

Evaluation of Substance Abuse, AIDS Impacts on Service Delivery In FY'90 the Office of Human Development Services will conduct an extensive study of the short and long-term impact of families with substance abuse problems or AIDS on service delivery within HDS programs (Head Start, Adoption Assistance, Runaway and Homeless Youth Centers, etc.).

OTHER HHS PROGRAMS AND ACTIVITIES

SOCIAL SECURITY ADMINISTRATION (SSA)

Medicaid. This entitlement program pays for the medical care of many low income persons, particularly those receiving AFDC. Although eligibility and covered services vary somewhat from state to state, many drug exposed infants, particularly crack babies who most often are born to low income single parents, are eligible for benefits. Congress has made efforts in recent years to expand Medicaid coverage for pregnant women and infants. Also, in 1988 a new waiver authority was made available to states as part of the Section 2176 waiver program, under which states can utilize Medicaid funds to pay for certain kinds of medical care in foster homes for children who are HIV infected, addicted to drugs at birth, or who have developed AIDS after birth.

SSI Disabled Children Program. This program, administered by the Social Security Administration, provides benefits to nearly 400,000 disabled or blind children and youth in low income families or in foster care and institutions. Drug exposed children could receive benefits if their disabilities fall within program guidelines.

The HHS Secretarial Access Initiative. The overall goal of this project is to improve pregnancy outcomes for low income and minority women by increasing their access to health care services. Among its six primary objectives is to target substance abuse prevention and treatment

funds to women of reproductive age, beginning with those pregnant and abusing drugs. The project is trying to coordinate existing infant related health programs, and deals with items in the FY90 and FY91 budgets, tracking the progress of projects and services.

Research and Evaluation Projects. A variety of HHS offices will conduct research projects in FY90 relating to drug exposed children and their families. A number of these are outlined below.

--**NIDA's** In Utero Drug Exposure Survey and the **Center for Disease Control's** Study of Cocaine Use in Pregnancy will each provide epidemiological data regarding drug using mothers and their children.

--**The Inspector General's office** intends to study the issue of boarder babies in the fourth quarter of FY'90. Few details are available regarding the anticipated scope of their report. They are currently studying the effects of crack on existing HDS programs.

--**The Health Resources and Services Administration** will conduct an assessment of prenatal and substance abuse services available to homeless, pregnant, substance abusing women in the Community/Migrant Health Centers. They will also fund several other evaluations which indirectly relate to this population.

The National Commission to Prevent Infant Mortality This interdepartmental group is putting together a report for the Domestic Policy Council. The charge of the Task Force is to review issues and propose solutions for the following: universal eligibility for public programs, health promotion and education, insurance and employment benefits, and community based health and social service delivery. One section of the draft report deals with drug abuse.

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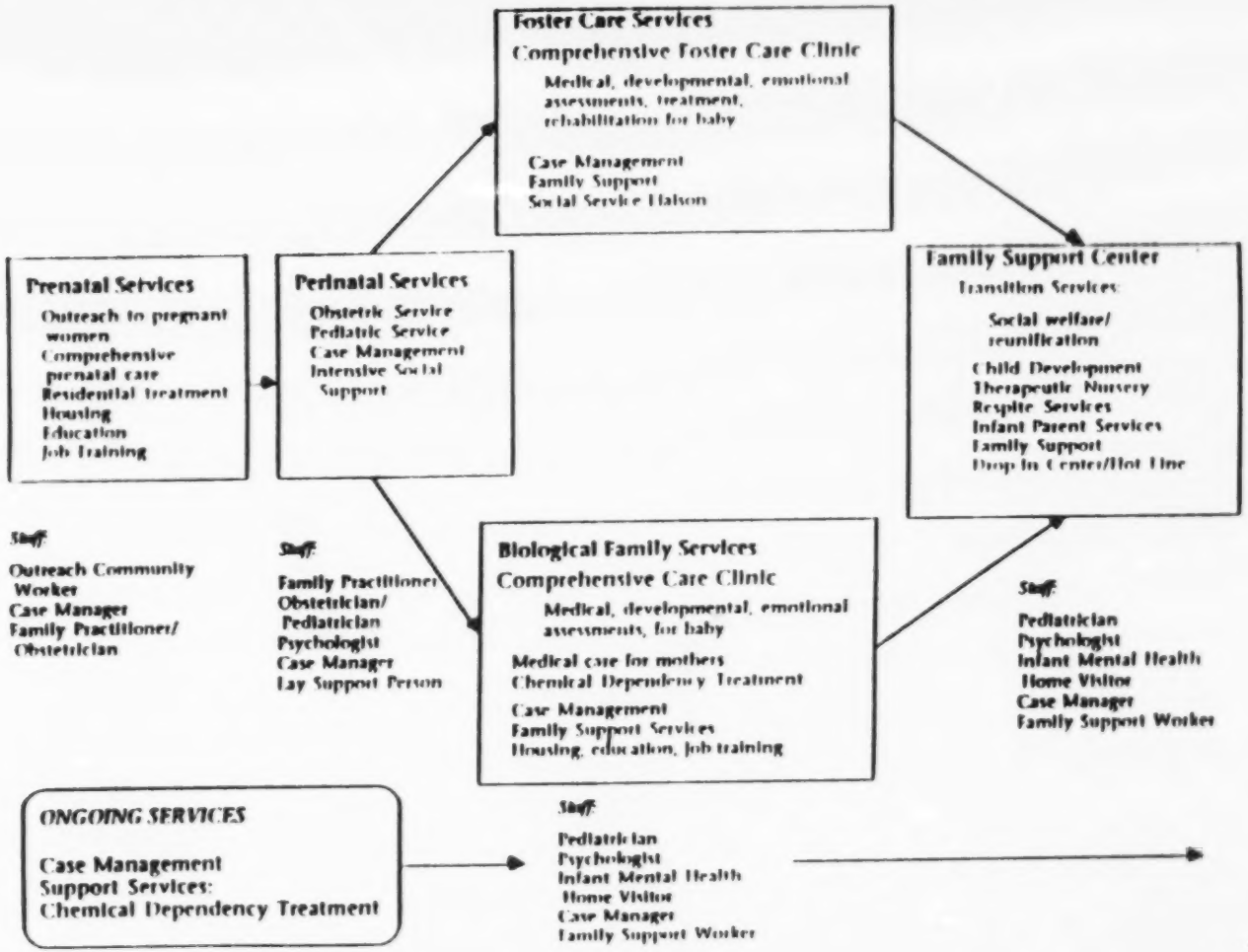
By Theodora Ooms and Lisa Herendeen
Family Impact Seminar
April 1990, Revised, June 1990.

CONTINUUM of CARE for CHEMICALLY DEPENDENT WOMEN & THEIR BABIES



From: Neal Halfon M.D. Congressional testimony provided at a hearing of the Select Committee on Children, Youth, and Families, House of Representatives on April 27th, 1989, held in Washington D.C. See Born Hooked: Confronting the Impact of Perinatal Substance Abuse. Hearing Report, page 83.

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